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ABSTRACT

A resource manual for the allied health professional who works with disabled children and youth is presented. Each of the manual's six units states objectives for the allied health student and provides resource materials and publications, and a bibliography. Unit 1 on Public Law 94-142 (the Education for All Handicapped Children Act), also provides information on provisions of Section 504 of the Rehabilitation Act of 1973 and parents' rights. Unit 2, concerning roles and responsibilities of allied health professionals considers the family's response to chronic childhood disability, the media's portrayal of the handicapped, mainstreaming, and the functions of various professionals. Unit 3, on identifying of children and youth with handicapping conditions, covers: the characteristics, classification, and remediation of various disabilities; normal early childhood development; diagnostic criteria for Head Start referrals; observational checklists; and developmental screening and child assessment. Unit 4, which covers communication strategies for effective delivery of service, includes 10 case studies and information on listening skills and communicating with disabled persons (e.g., the hearing impaired). Unit 5, on networking strategies for information exchange and referral, provides lists of national, regional, and state organizations concerned with the handicapped, as well as a discussion of the referral process. Unit 6, concerning advocacy, addresses the role of professionals and parents, change strategies, and advocacy and the federal budget process. (SEW)

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ALLIANCES
IN
ADVOCACY
FOR
DISABLED CHILDREN
AND
YOUTH

Project Director

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EC151643

This resource manual was developed for the Allied Health Child-Find and Advocacy Project through a grant awarded to the American Society of Allied Health Professions from the U.S. Department of Education, Office of Special Education and Rehabilitative Services. Grant Number G008001409.

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The materials contained in the Resource Manual are the result of the expertise and dedication of a number of people, including the Project's Advisory Council, Staff, Faculty, and Resource Consultants. The Allied Health Child-Find and Advocacy Project's Advisory Council provided the conceptualization for the workshop's content and instructional strategies, while the Project Staff and Faculty identified, obtained, and assembled the materials you find inside.

With sincere appreciation to each of our contributors, I wish to acknowledge particularly the countless hours contributed by my dedicated Project Staff:

- Karen Constine
  Student Intern
  University of California, Santa Barbara

- Mirdza Kains
  Project Assistant, Education Policy Fellow

- Barbara Kohl
  Administrative Assistant

In addition, I wish to acknowledge the invaluable consultation provided by our D.C. Resource Council, and particularly, Ms. Mary Ann Mc Dermott, Project Officer, Division of Personnel Preparation, Office of Special Education, U. S. Department of Education; Dr. Mark N. Ozer, Associate Professor, Child Health and Development, George Washington School of Medicine; and Dr. Marilyn Semmes, Coordinator for Handicapped Services, Head Start Project.

Carolyn M. Del Polito
Project Director

THE ALMOND TREE*

by

John Stallworthy

I

All the way to the hospital
the lights were green as peppermints.
Trees of black iron broke into leaf
ahead of me, as if
I were the lucky prince
in an enchanted wood
summoning summer with my whistle,
banishing winter with a nod.

Swung by the road from bend to bend,
I was aware that blood was running
down through the delta of my wrist
and under arches
of bright bone. Centuries,
continents it had crossed;
from an undisclosed beginning
spiralling to an unmapped end.

II

Crossing (at sixty) Magdalen Bridge
Let it be a son, a son, said
the man in the driving mirror,
Let it be a son. The tower
held up its hand: the college
bells shook their blessing on his head.

III

I parked in an almond's
shadow blossom, for the tree
was waving, waving me
upstairs with a child's hands.

IV

Up
the spinal stair
and at the top
along
a bone-white corridor
the blood tide swung
me swung me to a room
whose walls shuddered
with the shuddering womb.
Under the sheet
wave after wave, wave
after wave beat
on the bone coast, bringing
ashore -- whom?

---

*From _Root and Branch_ by Jon Stallworthy, London: Chatto and Windus, 1968.

New
minted, my bright farthing!
Coined by our love, stamped with
our images, how you
enrich us! Both
you make one. Welcome -
to your white sheet,
my best poem!

V

At seven-thirty
the visitors' bell
scissored the calm
of the corridors,
The doctor walked with me
to the slicing doors.

His hand upon my arm,
his voice -- _I have to tell_
you -- set another bell
beating in my head:
your son is a mongol
the doctor said.

VI

How easily the word went in --
clean as a bullet
leaving no mark on the skin,
stopping the heart within it.

This was my first death.
The "I" ascending on a slow
last thermal breath
studied the man below

as a pilot treading air might
the buckled shell of his plane --
boot, glove, and helmet
feeling no pain

from the snapped wires' radiant ends.
Looking down from a thousand feet
I held four walls in the lens
of an eye; wall, window, the street

a torrent of windscreens, my own
car under its almond tree,
and the almond waving me down.
I wrestled against gravity,

but the light was melting and the gulf
cracked open. Unfamiliar
the body of my late self
I carried to the car.

VII

The hospital - its heavy freight
lashed down ship-shape ward over ward -
steamed into night with some on board
soon to be lost if the desperate

charts were known. Others would come
altered to land or find the land
altered. At their voyage's end
some would be added to, some

diminished. In a numbered cot
my son sailed from me; never to come
ashore into my kingdom
speaking my language. Better not

look that way. The almond tree
was beautiful in labour. Blood-
dark, quickening, bud after bud
split, flower after flower shook free.

On the darkening wind a pale
face floated. Out of reach. Only when
the buds, all the buds, were broken
would the tree be in full sail.

In labour the tree was becoming
itself. I, too, rooted in earth
and ringed by darkness, from the death
of myself saw myself blossoming,

wrenched from the caul of my thirty
years' growing, fathered by my son,
unkindly in a kind season
by love shattered and set free.

VIII

You turn to the window for the first time.
I am called to the cot
to see your focus shift,
take tendril-hold on a shaft
of sun, explore its dusty surface, climb
to an eye you cannot

meet. You have a sickness they cannot heal,
the doctors say; locked in
your body you will remain.
Well, I have been locked in mine.
We will tunnel each other out. You seal
the covenant with a grin.

In the days we have known one another,
my little mongol love,
I have learnt more from your lips
than you will from mine perhaps;
I have learnt that to live is to suffer,
to suffer is to live.

ABOUT OUR FACULTY MEMBERS

TONY BASHIR

Dr. Anthony Bashir is a Senior in speech and language pathology, Division of Hearing & Speech, The Childrens Hospital Medical Center, Boston. He is also a lecturer on pediatric medicine at Harvard Medical School. Dr. Bashir also serves as Legislative Counselor from the Commonwealth of Massachusetts to the American Speech-Language-Hearing Association, as well as being a member of several national task forces that deal with language and hearing disabilities, especially the Joint National Committee for Hearing Disabilities.

CAROLYN M. DEL POLITO

Carolyn M. Del Polito, Ph.D. (Purdue University), as Director of the American Society of Allied Health Professions' Allied Health Child-Find and Advocacy Project, has been responsible for the implementation of the Project's Workshops and Conferences for Allied Health Professionals to recognize and accept their roles and responsibilities for disabled youngsters and their families. With degrees in Speech-Language-Pathology, Human Communication Theory, and Educational Psychology, Dr. Del Polito has had a wide range of experiences in education and administration, including university teaching, conference presentations and publications, and professional organization leadership (national and regional). Her research interests lie in the area of self-concept enhancement and communication systems in organizations--particularly health-care organizations.

ETHAN B. ELLIS, M.A.

Trained as a vocational rehabilitation counselor, Ethan B. Ellis directed vocational services and managed a sheltered workshop at Bird S. Coler Hospital in New York City for five years. In the early sixties, he developed vocational and social studies curricula for high school dropouts at a prototype antipoverity program on the Lower East Side and later directed the State of New Jersey's technical assistance unit for OEO funded community organizations. In 1976, he joined the staff of the Office of Advocacy for the Developmentally Disabled at the New Jersey Department of the Public Advocate. He is new Deputy Director of that program. He also serves as President of the National Association of Protection and Advocacy Systems.

ABOUT OUR FACULTY MEMBERS (CONT.)

SALLY PISARCHICK

Dr. Sally Pisarchick, currently Project Manager for the Instructional Resource Center serving Ohio's Cuyahoga County and Adjunct Professor at Kent State University, has taught special education and methods courses at the college level for the past fiften years. Dr. Pisarchick's background also includes eight years as a high school teacher and two years as a County Supervisor for Special Education.

JAYN WITTENMYER

A former teacher, Jayn Wittenmyer is parent to three daughters, one of whom is handicapped. It is because of her interest in securing meaningful services for her daughter that Jayn became involved in the volunteer work of the Association for Retarded Citizens. She has had local, state and national involvement in the volunteer movement. Currently, Jayn serves as Executive Director for the Wisconsin Departmental Disabilities Council. She states as her primary interest that of obtaining services for handicapped persons through the political and administrative arena.

ABOUT OUR ADJUNCT FACULTY

PETER ANDERSEN

Dr. Peter Andersen, currently Associate Professor of Speech Communication at West Virginia University, has been involved in teaching and researching communication for the past nine years. Along with numerous presentations and workshops in communication for teachers, lawyers, medical professionals, and law enforcement agencies, Dr. Andersen also has written widely on the subject. As of September, 1981, Dr. Andersen will be Associate Professor at San Diego State University.

SHIRLEY M. ATKINS

A native of West Virginia, Shirley M. Atkins graduated from West Virginia Wesleyan College, majoring in Sociology and Art. She spent a total of ten years teaching children with emotional disturbances and children with learning disabilities. Her graduate studies were in Special Education and Higher Education.

Dr. Atkins is an Associate Professor and an Assistant Dean in the School of Health Related Professions at the University of Pittsburgh. She has participated in and led a variety of workshops and training sessions at the local level and also functions as Affirmative Action Officer in the School of Health Related Professions.

ORIENTATION

GOALS AND OBJECTIVES

Small Group Session I: **Participant Introductions**

Purpose:

To provide time for participants to meet one another.

Specific Objectives:

At the conclusion of this session, participants should:

1. Know the names and home communities of the other members of their small groups;
2. Understand the professional roles each member represents;
3. Understand the extent to which their small group members interact with handicapped children and youth; and
4. Recognize the diversity of the backgrounds, expertise, and motivations represented in their groups and, therefore, in the workshop generally.

UNIT I: THE LAW

GOALS AND OBJECTIVES

Perspectives on the Law: Rights of Handicapped Children and Youth

Purpose:

To discuss the implications of PL 94-142 and Section 504 for handicapped children and youth from the unique perspectives of each of five panel members: the special educator, the regular educator, the parent, the handicapped consumer, and the Allied Health professional. A question and answer period will follow.

Specific Objectives:

At the conclusion of this session, participants should:

1. Understand the implications of federal legislation for the rights of handicapped children and youth, including their rights to:
    a. a free and appropriate education;
    b. access to services, programs, and facilities;
    c. due process;
    d. equal opportunity based on capability;
    e. a least restrictive educational environment;
    f. Individualized Education Programs (IEP); and
    g. related services.
2. Understand there are differences between federal and state legislation regarding the rights of handicapped children and youth and their families.
3. Be more sensitive to the educational and health-related service needs of handicapped children and youth.

GENERAL SESSION I

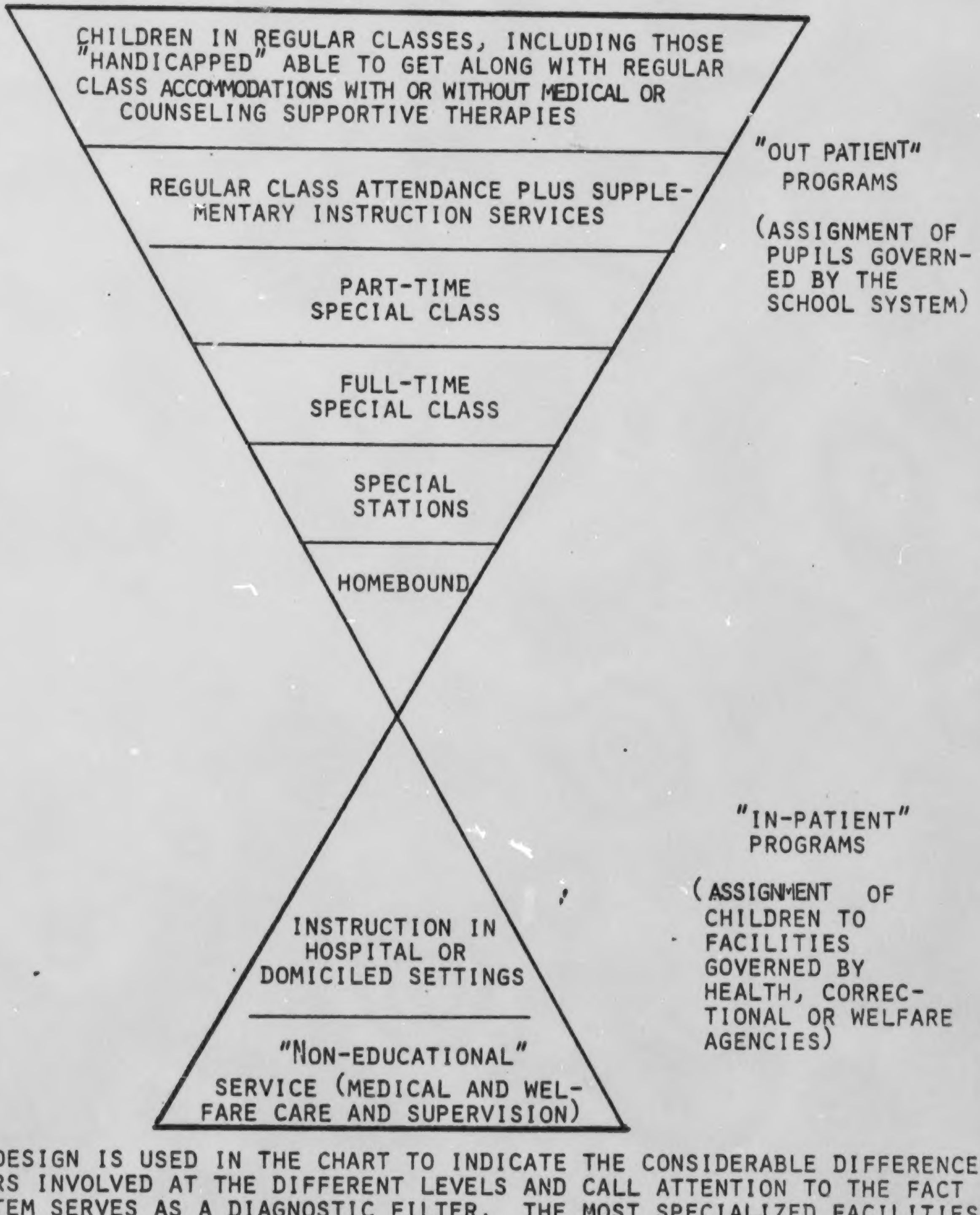
PERSPECTIVES ON THE LAW: RIGHTS OF HANDICAPPED CHILDREN AND YOUTH

DR. SALLY E. PISARCHICK, DIRECTOR
CUYAHOGA SPECIAL EDUCATION SERVICE CENTER

KEY MANDATES OF PUBLIC LAW 94-142

1. CHILD IDENTIFICATION AND ACCOUNTING
2. NON-BIASED ASSESSMENT
3. MULTI-FACTORED ASSESSMENT
4. INDIVIDUAL EDUCATION PROGRAM
5. DUE PROCESS SAFEGUARDS
6. LEAST RESTRICTIVE ALTERNATIVES
7. CONFIDENTIALITY OF RECORDS
8. FULL SERVICES GOAL BY 1980 FOR ALL HANDICAPPED CHILDREN, AGES 3 TO 21 YEARS

STRATEGIES AND MODELS IN SPECIAL EDUCATION


CHILDREN IN REGULAR CLASSES, INCLUDING THOSE "HANDICAPPED" ABLE TO GET ALONG WITH REGULAR CLASS ACCOMMODATIONS WITH OR WITHOUT MEDICAL OR COUNSELING SUPPORTIVE THERAPIES
REGULAR CLASS ATTENDANCE PLUS SUPPLEMENTARY INSTRUCTION SERVICES
PART-TIME SPECIAL CLASS
FULL-TIME SPECIAL CLASS
SPECIAL STATIONS
HOMEBOUND
"OUT PATIENT" PROGRAMS
(ASSIGNMENT OF PUPILS GOVERNED BY THE SCHOOL SYSTEM)
INSTRUCTION IN HOSPITAL OR DOMICILED SETTINGS
"NON-EDUCATIONAL" SERVICE (MEDICAL AND WELFARE CARE AND SUPERVISION)
"IN-PATIENT" PROGRAMS
(ASSIGNMENT OF CHILDREN TO FACILITIES GOVERNED BY HEALTH, CORRECTIONAL OR WELFARE AGENCIES)

THE TAPERED DESIGN IS USED IN THE CHART TO INDICATE THE CONSIDERABLE DIFFERENCE IN THE NUMBERS INVOLVED AT THE DIFFERENT LEVELS AND CALL ATTENTION TO THE FACT THAT THE SYSTEM SERVES AS A DIAGNOSTIC FILTER. THE MOST SPECIALIZED FACILITIES ARE LIKELY TO BE NEEDED BY THE FEWEST CHILDREN ON A LONG-TERM BASIS. THIS ORGANIZATION MODEL CAN BE APPLIED TO DEVELOPMENT OF SPECIAL EDUCATION SERVICES FOR ALL TYPES OF DISABILITY.

FIGURE 2.

THE CASCADE SYSTEM OF SPECIAL EDUCATION SERVICE (EVELYN DENO)

LEAST RESTRICTIVE ALTERNATIVES

..."TO THE MAXIMUM EXTENT APPROPRIATE, HANDICAPPED CHILDREN - INCLUDING CHILDREN IN PUBLIC OR PRIVATE INSTITUTIONS OR OTHER CARE FACILITIES - SHALL BE EDUCATED WITH CHILDREN WHO ARE NOT HANDICAPPED".
(P.L. 94-142 - AMEND. SUB. HOUSE BILL 455)

1. MEET UNIQUE NEEDS OF EACH CHILD
2. REMOVE FROM REGULAR EDUCATIONAL ENVIORMENT
   ONLY WHEN NATURE/SEVERITY OF HANDICAP
   FORCES SUCH A PLACEMENT
3. APPLY CONTINUUM OF SERVICES AND/OR
   SUPPLEMENTARY AIDS AND SERVICES

CHILD IDENTIFICATION AND ACCOUNTING

1. WRITTEN POLICIES AND PROCEDURES
2. INCORPORATED IN LOCAL EDUCATION ASSOCIATION COMPREHENSIVE PLAN
3. IN-SCHOOL
    - A. ON-GOING
    - B. SYSTEMATIC
4. OUT-OF-SCHOOL
    - A. ON-GOING
    - B. BIRTH THROUGH AGE 21
    - C. A HOUSEHOLD CONTACT AT LEAST ONCE IN THREE YEAR PERIOD
5. DATA MONITORING, COLLECTING, AND REPORTING
    - A. UNSERVED
    - B. REASONS UNSERVED
    - C. SERVED
    - D. COLLATION OF DATA BY SPECIAL EDUCATION REGIONAL RESOURCE CENTER (SERRC)

NON-BIASED ASSESSMENT

1. RACIAL/CULTURAL-FREE EVALUATIONS
2. ADMINISTERED IN CHILD'S NATIVE LANGUAGE OR MODE OF COMMUNICATION

MULTI-FACTORED ASSESSMENT

1. EVALUATION OF MORE THAN ONE AREA OF FUNCTIONING
    ADAPTIVE BEHAVIOR
    ACADEMIC ACHIEVEMENT
    COMMUNICATION SKILLS
    COGNITIVE FUNCTIONING
    . . . . . (ETC.)
2. VARIETY OF INSTRUMENTS AND METHODS

INDIVIDUAL EDUCATION PROGRAM

... "A WRITTEN STATEMENT FOR EACH HANDICAPPED CHILD DESIGNED TO MEET THE UNIQUE NEEDS OF CHILD".

(AMEND. SUB. HOUSE BILL 455)

1. STATEMENT OF PRESENT LEVELS OF PERFORMANCE
2. STATEMENT OF SPECIFIC EDUCATIONAL SERVICES NEEDED
3. ANNUAL GOALS
4. SHORT TERM INSTRUCTIONAL OBJECTIVES
5. DATE OF INITIATION AND DURATION OF SERVICES
6. ANNUAL REVIEW

DUE PROCESS SAFEGUARDS

... SAFEGUARDS IN RELATION TO THE IDENTIFICATION, EVALUATION, OR EDUCATIONAL PLACEMENT...
(AMEND. SUB. HOUSE BILL 455)

1. APPOINTMENT OF PARENT SURROGATE
2. INSPECT AND REVIEW
3. PRIOR NOTICE AND WRITTEN PERMISSION TO IDENTIFY, EVALUATE, OR CHANGE THE PLACEMENT OF A CHILD
4. NOTIFICATION OF ANNUAL REVIEW
5. PRESENT COMPLAINTS
    - A. CASE CONFERENCE
    - B. PLACEMENT TEAM CONFERENCE
    - C. ADMINISTRATIVE REVIEW
    - D. IMPARTIAL HEARING
    - E. STATE LEVEL REVIEW
    - F. APPEAL TO THE COURTS

CONFIDENTIALITY OF RECORDS

. . . PROTECT AND ASSURE CONFIDENTIALLY OF PERSONALLY IDENTIFIABLE DATE AT COLLECTION, STORAGE DISCLOSURE AND DESTRUCTION.

1. WRITTEN POLICIES AND PROCEDURES AVAILABLE TO PARENTS/ELIGIBLE STUDENTS
2. PARENT/ELIGIBLE STUDENT RIGHT TO INSPECT/REVIEW OF EDUCATION RECORDS
3. ANNUAL NOTIFICATION OF RIGHTS AND POLICIES
4. DESTRUCTION OF DATA
    A. WITHIN FIVE YEARS FOLLOWING NEED
    B. PERMANENT RECORD MAY BE MAINTAINED
        NAME, ADDRESS, PHONE NUMBER
        BIRTHDATE
        GRADES
        ATTENDANCE RECORD
        GRADE LEVEL COMPLETED

FREE AND APPROPRIATE EDUCATION FOR ALL HANDICAPPED CHILDREN

1. SPECIAL EDUCATION AND RELATED SERVICES PROVIDED AT PUBLIC EXPENSE, REGARDLESS OF HANDICAP.
2. MEET STATE STANDARDS
3. INCLUDES ELEMENTARY AND SECONDARY EDUCATION, MAY INCLUDE PRE-SCHOOL
4. INCLUDES AN INDIVIDUALIZED EDUCATIONAL PROGRAM (I.E.P.)
5. STATE PLAN INCLUDE:
    A. TIMETABLE FOR ACHIEVEMENT OF FULL SERVICES
    B. DESCRIPTION OF FACILITIES, PERSONNEL, & SERVICES
6. DEADLINES (P.L. 94-142)
    A. AGE 3-18, SEPT. 1, 1978
    B. AGE 3-21, SEPT. 1, 1980

UNIT I: THE LAW

RESOURCES

- Key Provisions of PL 94-142 and Section 504 - an overview.
- Definition of "related services" as used in PL 94-142.
- Federal Register/Volume 46, No. 12, Monday, January 19, 1981, pages 4912 and 4913.
  "...to provide clean intermittent catheterization as a 'related service'..."
- Federal Register/Volume 45, No. 251/Tuesday, December 30, 1980. Pages 86390 and 86391.
  "...concerning the use of parents' insurance proceeds to pay for required services..."
- No Discrimination/No Barrier in Education, Employment, and Service Programs by the Parent Information Center, CCHC, 407 S. Dearborn Street, Room 1075, Chicago, IL 60605.
- Evaluation, Placement and Due Process Under PL 94-142 and Section 504.
- You Have New Rights - Use Them! by Closer Look.
- Fact Sheet: Your Child's School Records, by CCHC.
- Content of the IEP and sample IEP.
- How to Be Assertive at Your Child's IEP.
- How to Prepare for a Due Process Hearing.
- True-False Test Regarding PL 94-142.
- Bibliography.

KEY PROVISIONS OF PUBLIC LAW 94-142 and SEC. 504

MAJOR REQUIREMENTS FOR EDUCATION OF HANDICAPPED IN SCHOOLS

A. CHILD IDENTIFICATION AND ACCOUNTING:
   1. Written policies and procedures
   2. School district comprehensive plan for handicapped education
   3. In-School Child Find: on-going and systematic
   4. Out-of-School Child Find: on-going, 0-21; each household contact three years
   5. Data monitoring, collecting and reporting of unserved, reasons; and served

B. NON-BIASED ASSESSMENT:
   1. Racial/cultural-free evaluations
   2. Administered in child's native language or mode of communication
   3. Renewed at least once each three years

C. MULTI-FACTORED ASSESSMENT:
   1. Evaluation of more than one area of functioning: adaptive behavior, academic achievement, communication skills, cognitive functioning, etc....
   2. Use variety of instruments and methods

D. INDIVIDUALIZED EDUCATION PROGRAM (PLAN):
   1. "...written statement for each handicapped child designed to meet the unique needs of child..."
   2. I.E.P. includes:
      a. Statement of present levels of performance
      b. Statement of specific educational services to be provided (including related services)
      c. Extent to which child will be able to participate in regular program
      d. Statement of Annual Goals, including short term instructional objectives
      e. Projected dates for initiation of services and duration
      f. Appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short term instructional objectives are being achieved.

E. DUE PROCESS SAFEGUARDS:
   1. Appointment of parent surrogate
   2. Inspect and review records
   3. Prior notice and written permission to identify, evaluate
   4. Prior notice, right to complain of placement or change
   5. Notification of annual review (periodic)
   6. Present complaints or secure information through:
      a. Case conference
      b. Placement Team conference
      c. Administrative Review
      d. Impartial Hearing
      e. State Level Review
      f. Appeal to courts

F. LEAST RESTRICTIVE ALTERNATIVE PLACEMENT:
1. Meet unique needs of EACH child
2. Remove from regular educational environment ONLY when nature/severity of handicap prevents being met with supplementary aids, etc.
3. Apply continuum of services and/or supplementary aids and services

G. CONFIDENTIALITY OF RECORDS:
1. Written policies and procedures available to parents
2. Parent right to inspect/review educational records
3. Annual notification of rights and policies
4. Destruction of data: within five years if no longer needed must notify, offer records if destroyed; retain name, address, phone, birthdate, grades, attendance record, grade levels completed.

H. FREE APPROPRIATE PUBLIC EDUCATION FOR ALL HANDICAPPED:
1. Special education and related services provided at public expense regardless of handicap
2. Meets state standards
3. Includes elementary and secondary education, may include pre-school (as per state decision/provision)
4. Includes IEP for every child
5. State plan must include timetable for achievement of full services and description of facilities, personnel and services
6. Deadlines (94-142/504) require admit every handicapped child 5-21 and provide an appropriate program placement and related services by 9/78; also diagnostic assessment services to 0-4 and placement if available

"No otherwise qualified handicapped individual in the U.S.... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."
Sec. 504, P.L.93-112.

The term "related services" as used in PL 94-142 is defined in Section 121a.13 of the regulations. It means:

> ...transportation and such developmental, corrective, and other supportive services as are required to assist a handicapped child to benefit from special education, and includes speech pathology and audiology, psychological services, physical and occupational therapy, recreation, early identification and assessment of disabilities in children, counseling services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling.

(The terms within this definition are further defined in the same section.) The comment to Section 121a.13 states, however, that:

> The list of related services is not exhaustive and may include other developmental, corrective, or supportive services (such as artistic and cultural programs, and art, music, and dance therapy) if they are required to assist a handicapped child to benefit from special education.
>
> There are certain kinds of services which might be provided by persons from varying professional backgrounds and with a variety of operational titles, depending upon requirements in individual States. For example, counseling services might be provided by social workers, psychologists, or guidance counselors; and psychological testing might be done by qualified psychological examiners, psychometrists, or psychologists, depending upon State standards.
>
> Each related service defined under this part may include appropriate administrative and supervisory activities that are necessary for program-planning, management, and evaluation.

DEPARTMENT OF EDUCATION

Office of Special Education

34 CFR Parts 104 and 300

Assistance to States for Education of Handicapped Children, and Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance; Notice of Interpretations

AGENCY: Department of Education.

ACTION: Notice of Interpretation.

SUMMARY: The Secretary of Education interprets Part B of the Education of the Handicapped Act and Section 504 of the Rehabilitation Act of 1973 to require public educational agencies to provide clean intermittent catheterization as a "related service" when it is required to provide a free appropriate public education, including services in the least restrictive environment, to handicapped children who are entitled to receive services under those statutes. This interpretation is issued in response to public inquiries regarding Department policy on the matter.

EFFECTIVE DATE: This interpretation is expected to take effect 45 days after it is transmitted to Congress. Interpretations are usually transmitted to Congress several days before they are published in the **Federal Register**. The effective date of interpretations that are subject to the transmittal requirement is changed by statute if Congress takes certain adjournments. Although the interpretation of Section 504 is not subject to this requirement, the Secretary has decided to set its effective date for the same day as the interpretation of Part B of the Education of the Handicapped Act. If you want to know the effective date of this interpretation, call or write the Department of Education contact persons.

FOR FURTHER INFORMATION CONTACT:

Ms. Shirley A. Jones, Office of Special Education, Department of Education, Donohoe Building, 4th Floor, 400 Maryland Avenue, S.W., Washington, D.C. 20202, telephone: (202) 472-7921.

Mr. Edward A. Stutman, Office for Civil Rights, Department of Education, Switzer Building, Room 5430, 300 C Street, S.W., Washington, D.C. 20202, telephone: (202) 245-0781.

SUPPLEMENTARY INFORMATION:

The Issue

The issue presented is whether Part B of the Education of the Handicapped Act, as amended ("Part B"; 20 U.S.C. 1411-1420) and its regulations (34 CFR Part 300; formerly 45 CFR Part 121a) and Section 504 of the Rehabilitation Act of 1973, as amended ("Section 504"; 29 U.S.C. 794) and its regulations (34 CFR Part 104; formerly 45 CFR Part 84) require public educational agencies to provide clean intermittent catheterization as a related service to eligible handicapped children when those children require the service to receive a free appropriate public education, including services in the least restrictive environment.

The Interpretation

Both Part B and Section 504 require public educational agencies to provide clean intermittent catheterization as a "related service" to handicapped children who are entitled to receive services under those statutes, when it is required to provide a free appropriate public education, including services in the least restrictive environment.

Background

A procedure called "clean intermittent catheterization" "(CIC)" is often recommended for physically handicapped children who have impaired function of the urinary bladder. It is usually a relatively simple procedure to administer with minimal training and can be performed by a school nurse, the individual requiring catheterization, or another responsible person, none of whom need to be licensed to perform the service. Therefore, for the limited purpose of interpretating Part B or Section 504, the Secretary does not interpret CIC to be a medical service. In fact, a number of educational agencies are not providing this service to handicapped children as a part of their school health services. A report on the use of CIC accepted and endorsed by the Urology Section of the American Academy of Pediatrics on October 23, 1978, states that "CIC in infancy must be carried out by an adult, but with normal intelligence most children are able to self-catheterize from approximately six to seven years of age, sometimes even earlier."

While the number of children in the United States who currently require assistance with CIC cannot be stated with precision, those children who most often use CIC have myelodysplasia (spine bifida), which medical authorities estimate to occur in 1–2 live births per thousand in the United States. However, not all children with spina bifida require catheterization, and the majority of children who are catheterized do not require assistance with catheterization throughout the years they attend elementary and secondary school.

Part B

Under Part B of the Education of the Handicapped Act, a handicapped child within the eligible age ranges is entitled to receive a free appropriate public education, a term defined in Section 602 of the Act to include special education and related services. 20 U.S.C. 1401. The term "related services" is defined in Section 602(17) to mean:

> "* * * transportation, and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, and medical and counseling services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a handicapped child to benefit from special education, and * * * the early identification and assessment of handicapping conditions in children."

The regulations implement this section by defining each statutorily-specified related service, and by specifying other services, including school health services, as well. Moreover, while catheterization is not specifically listed as a "related service", the "Comment" that follows 34 CFR 300.13 states:

> "The list of related services is not exhaustive and may include other developmental, corrective, or supportive services * * * if they are required to assist a handicapped child to benefit from special education."

In addition to the related services requirements outlined above, each public agency must ensure that to the maximum extent appropriate, handicapped children are educated with children who are not handicapped, and that special classes, separate schooling, or other provision of education to handicapped children outside of the regular environment occurs only when the nature or severity of the handicap is such that education in the regular classes cannot be satisfactorily achieved with the use of supplementary aids and services. 20 U.S.C. 1412(5)(B); 34 CFR 300.550.

In light of the above, the Secretary concludes that clean intermittent catheterization is a "related service" as that term is defined in the Education of the Handicapped Act. CIC must be provided when it is required to provide a free appropriate public education, including services in the least restrictive environment, to handicapped children receiving special education. A public agency is not required to provide CIC to a child who is enrolled in a day program when that child is not in school. Nor is the agency required to provide routine medical services, such as laboratory analysis, that may be related to the provision of CIC. (These services are also not required under Section 504.)

Section 504

Under Section 504 and the Department's implementing regulation, public educational agencies are required to provide regular or special education and related aids and services to eligible handicapped children. 34 CFR 104.3(j), 104.3(k)(2). Those handicapped children entitled to services under Section 504 must be provided a free appropriate public education "regardless of the nature or severity of the person's handicap". 34 CFR 104.33(a). Moreover, Section 104.34 of the regulation requires that handicapped persons be educated in the regular educational environment unless this cannot be satisfactorily achieved with the use of supplementary aids and services.

Therefore, the Secretary concludes that, under Section 504, clean intermittent catheterization is a "related service" when it is necessary to ensure the provision of a free appropriate public education, including services in the least restrictive environment, for handicapped children requiring regular or special education.

Judicial Precedent

The limited judicial precedent on catheterization as a required service is consistent with the Secretary's interpretation. See *Tatro* v *State of Texas*, 625 F.2d 557 (5th Cir. 1980); *Tokarcik* v. *Forest Hills School District*, No. 79–338 (W.D. Pa. Oct. 31, 1980); and *Hairston* v. *Drosick*, 423 F. Supp. 180 (S.D. W.Va. 1976). In the cases decided after publicaition of regulations under Part B and Section 504, the courts held that CIC is a related service which must be provided to handicapped children. In the case decided before publication of the regulations, the court held that a handicapped child could not be excluded from the regular classroom because she needed CIC.

(20 U.S.C. 1401, 1411–1420; 29 U.S.C. 794)

Dated: January 13, 1981.

Shirley M. Hufstedler,

Secretary of Education.

[FR Doc. 81-1883 Filed 1-16-81; 8:45 am]

BILLING CODE 4000-01-M

DEPARTMENT OF EDUCATION

Office of Special Education

Office for Civil Rights

34 CFR Part 104 and 300

Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting From Federal Financial Assistance; and Assistance to States for Education of Handicapped Children

AGENCY: Department of Education.

ACTION: Notice of Interpretation.

SUMMARY: The Secretary of Education interprets Part B of the Education of the Handicapped Act, as amended, and Section 504 of the Rehabilitation Act of 1973, as amended, concerning the use of parents' insurance proceeds to pay for required services. It is the Secretary's interpretation that these statutes and their implementing regulations do not permit an educational agency responsible for the education of a handicapped child to require the parents of that child to use private insurance proceeds to pay for required services where the parents would incur financial loss. This interpretation is issued in response to public inquiries regarding Departmental policy on the matter.

EFFECTIVE DATE: This interpretation is expected to take effect 45 days after it is transmitted to Congress. Interpretations are usually transmitted to Congress several days before they are published in the **Federal Register**. The effective date of interpretations that are subject to the transmittal requirement is changed if Congress takes certain adjournments. Although the interpretation of Section 504 is not subject to this requirement, the Secretary has decided to set its effective date for the same day that the interpretation of Part B of the Education of the Handicapped Act becomes effective. If you want to know the effective date of this interpretation, call or write the Department of Education contact persons.

FOR FURTHER INFORMATION CONTACT: Ms. Shirley A. Jones, Office of Special Education, Department of Education, Donohoe Building, Room 4030, 400 Maryland Ave. S.W., Washington, D.C. 20202, telephone: (202) 472–7921. Mr. Edward A. Stutman, Office for Civil Rights, Department of Education, Switzer Building, Room 5430, 300 C St., S.W., Washington, D.C. 20202, telephone: (202) 245–0781.

SUPPLEMENTARY INFORMATION:

The Issue

The issue is whether Part B of the Education of the Handicapped Act, as amended, ("Part B"; 20 U.S.C. 1411–1420) and its regulations (34 CFR Part 300; formerly 45 CFR Part 121a) and Section 504 of the Rehabilitation Act of 1973, as amended ("Section 504"; 29 U.S.C. 794) and its regulations (34 CFR Part 104; formerly 45 CFR Part 84) permit an educational agency responsible for the education of a handicapped child to require the child's parents to file insurance claims and use the proceeds to pay for services that must be provided to the child under Part B and Section 504.

The Interpretation

Both Part B and Section 504 prohibit a public agency from requiring parents, where they would incur a financial cost, to use insurance proceeds to pay for services that must be provided to a handicapped child under the "free appropriate public education" requirements of those statutes. The use of parents' insurance proceeds to pay for services in these circumstances must be voluntary on the part of the parents.

Discussion

Under Section 612(2)(B) of Part B (20 U.S.C. 1412(2)(B)), each participating State must make available to all handicapped children within specified ages a free appropriate public education. "Free appropriate public education" is defined in Section 602(18) of the Education of the Handicapped Act, as amended, (20 U.S.C. 1401(18)) as "special education and related services which are provided at public expense, under public supervision and direction, and without charge. . . ." The requirement to provide these services is implemented in 34 CFR 300.300 *et seq.*

Similarly, the Department's regulations implementing Section 504 require any recipient of Federal financial assistance that operates a public elementary or secondary education program to "provide a free appropriate public education to each qualified handicapped person who is in the recipient's jurisdiction, regardless of the nature or severity of the person's handicap." 34 CFR 104.33(a). The provision of a free education is defined as "the provision of educational and related services without cost to the handicapped person or to his or her parents or guardian, except for those fees that are imposed on non-handicapped persons or their parents or guardian." 34 CFR 104.33(c).

The Secretary interprets the requirements that a free appropriate public education be provided "without charge" or "without cost" to mean that an agency may not compel parents to file an insurance claim when filing the claim would pose a realistic threat that the parents of handicapped children would suffer a finanial loss not incurred by similarly situated parents of non-handicapped children. Financial losses include, but are not limited to, the following:

(1) A decrease in available lifetime coverage or any other benefit under an insurance policy;

(2) An increase in premiums or the discontinuation of the policy; or

(3) An out-of-pocket expense such as the payment of a deductible amount incurred in filing a claim.

Financial losses do not include incidental costs such as the time needed to file an insurance claim or the postage needed to mail the claim.

The statutory and regulatory provisions relating to a free appropriate public education guarantee freedom only from financial loss as described above. Therefore, when the educational agency pays the financial costs related to filing a claim and no other cost (such as those listed above) is imposed, the parent suffers no financial loss. In addition, an agency may insist that parents file a claim when they would incur only minor incidental costs such as the time required to complete the form. The agency may require the parents to file a claim if it ensures that parents do not have to bear even a short-term financial loss. For example, if benefits begin only after a $50.00 deductible, the agency may insist that the parents file a claim if it pays for the services and the deductible in advance.

(20 U.S.C. 1401, 1411–1420; 29 U.S.C. 794)

The responsibility to make available a free appropriate public education does not mean that a public educational agency must use only its own funds for that purpose. An agency may use whatever State, local, Federal, and private sources of support are available to pay for required services. See 34 CFR 300.301(a) and 34 CFR 104.33(c)(1). Moreover, nothing in the Part B or Section 504 regulations relieves an insuror or similar third party from an otherwise valid obligation to provide or pay for services to a handicapped child. See 34 CFR 300.301(b) and 34 CFR 104.33(c).

Call for Public Comment

The Secretary is interested in receiving public comments on the extent to which the Department should provide further guidance on the use of insurance proceeds or other sources of funds to pay for services to handicapped children, and on the relationship between educational agencies and insurance carriers. These comments may be sent at any time to the Department contact persons identified in the beginning of this document.

Dated: December 22, 1980.

Shirley M. Hufstedler,

Secretary of Education.

[FR Doc. 80-40416 Filed 12-29-80; 8:45 am]

BILLING CODE 4000-01-M

SECTION 504 and the EDUCATION of HANDICAPPED CHILDREN

The education provisions of SECTION 504 are closely coordinated with P.L. 94-142 (the Education for All Handicapped Children Act), signed into law November 29, 1975. Provisions of both P.L. 94-142 and the education provisions of SECTION 504 become effective September 1, 1978.

REQUIREMENTS:

All recipients of HEW funds which operate public elementary or secondary education programs must "provide a free appropriate public education to each qualified handicapped person who is in the recipient's jurisdiction, regardless of the nature or severity of the person's handicap". (S 84.33)

SECTION 504 PROHIBITS DISCRIMINATION BY:

- *Public and Private Pre-School Programs*
- *Public and Private Day Care Centers*
- *Public and Private Adult Education Programs*
- *Public and Private Elementary and Secondary Education Programs*

DEFINITION: APPROPRIATE EDUCATION and FREE EDUCATION

"the provision of an APPROPRIATE EDUCATION is the provision of regular or special education and related aids and services that (i) are designed to meet individual educational needs of handicapped persons as adequately as the needs of non-handicapped persons are met and (ii) are based upon adherence to procedures that satisfy the requirements of SS 84.43, 84.35, 84.36".

(S 84.33)

"the provision of a FREE EDUCATION is the provision of educational and related services without cost to the handicapped person or to his or her parents or guardian, except for those fees that are imposed on non-handicapped persons or their parents or guardians. ...if a recipient places a handicapped person in or refers such person to a program not operated by the recipient as its means of carrying out the requirements of this subpart, it may consist of payment for the costs of the program".

REQUIREMENTS:

- *Annual identification of handicapped children by public school districts*
- *Annual notification to parents of handicapped children's rights to special education services*
- *Implementation of an Individualized Education Program, in accordance with P.L. 94-142*
- *Pre-placement evaluation*
- *Evaluation procedures which "accurately reflect the student's aptitude or achievement level"*
- *Placement procedures which ensure proper documentation of information and which involve persons knowledgeable about the child in placement decisions*
- *Mainstreaming in educational programs and other activities*
- *Parent access to school records and confidentiality as to contents*
- *Periodic reevaluation of handicapped children*
- *Transportation to educational programs*
- *Procedurel safeguards and Due Process Procedures which involve parents*
- *FREE RESIDENTIAL PLACEMENT (when such placement is necessary to meet educational needs of handicapped children)*
- *Equal opportunity for handicapped students to participate in:*
  - *non-academic services*
  - *health services*

PARENT
INFORMATION
CENTER
PIC

A subsidiary of
CO-ORDINATING COUNCIL
for HANDICAPPED CHILDREN
407 S. Dearborn St. room 1075
Chicago, Ill. 60605 (312) 939-3513

NO DISCRIMINATION / NO BARRIER

in Education, Employment, and Service Programs

(Summary of Section 504, Rehabilitation Act of 1973 - P.L. 93–112)

SECTION 504 has been called "the FIRST FEDERAL CIVIL RIGHTS LAW protecting the Rights of the Handicapped". It provides that: "no...qualified handicapped individual...shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance". (SECTION 504 - of the Rehabilitation Act of 1973, 29 U.S.C., 706 (S 84.4)

HISTORY

SECTION 504 is part of the Rehabilitation Act of 1973 (P.L. 93-112) and became law that year. At that time, Section 504 specifically applied only to discrimination in employment. In 1974, the Rehabilitation Act Amendments of 1974 (P.L. 93-516) extended coverage of Section 504 to all areas of civil rights including: education, post-secondary education, vocational training, employment, health, welfare, and other social service programs. (Preamble)

SECTION 504 RULES AND REGULATIONS went into effect April 28, 1977, when they were signed by HEW Secretary Joseph A. Califano, Jr. SECTION 504 applies to all recipients of HEW (Health, Education, and Welfare) funds, including:

.States, Counties, Cities, Towns, Villages, and their political subdivisions
.Instrumentalities of states and their political subdivisions
.Public and Private Schools
.Public and Private Institutions
.Public and Private Colleges
.Public and Private Hospitals, clinics
.Other health service providers
.Public and Private agencies
.Other organizations and entitities receiving HEW funds
(S 84.2)

DEFINITION: HANDICAPPED PERSON

"Any person who:
. Has a physical or mental impairment which substantially limits one or more major life activities
. Has a record of such an impairment
. Is regarded as having such an impairment"
. Is a drug addict or an alcoholic
(S 84.3)

DISCRIMINATION IS PROHIBITED IN:

. Education of Handicapped Children
. Vocational Education Programs
. College Programs and Other Postsecondary Education Programs
. Employment
. Health, Welfare, and Other Social Service Programs
. Other Programs and Activities Funded by HEW

ACCESSIBILITY
Service providers and employers are required to make "reasonable accommodation" to make programs, services and facilities accessible to the handicapped.

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The National Information Center
for the Handicapped

- *extra-curricular activities*
- *recreational programs*
- *athletics*
- *counseling services*
- *special interest groups or clubs sponsored by the School*
- *transportation*
- *referrals to service providers*
- *referrals for employment purposes*

S 84.34 - 84.37

SECTION 504 and POST-SECONDARY EDUCATION

All post-secondary education programs and activities - including colleges and post-secondary vocational education programs and activities - are covered by SECTION 504.

REQUIREMENTS:

All recipients of HEW funds which operate colleges and other post-secondary education programs and activities are prohibited from discriminating against handicapped persons in:

. *Admissions*
. *Admissions tests (Admissions tests must be administered "so as best to ensure that ...the test results accurately reflect the applicant's aptitude or achievement level...")*
. *Pre-admission inquiries about applicant's handicap - except to implement policies of Affirmative Action*
. *Academic Programs*
. *Research Programs*
. *Course Examinations*
. *Occupational Training Programs*
. *Health Programs*
. *Counseling Programs*
. *Insurance Programs*
. *Financial Assistance Programs*
. *Physical Education Programs*
. *Athletic Programs*
. *Recreation Programs*
. *Transportation Programs*
. *Extracurricular Activities*
. *Student Employment and placement services*
. *Social and Fraternal Organizations which receive assistance from the recipient*
. *Housing*
. *Other Programs and Activities receiving federal funds*

(S 84.41-50)

ALSO PROHIBITED:

. *Rules that limit participation of handicapped students in educational program and/or activity*
. *Denial of auxiliary aids such as:*
  - *taped texts and tape recorders*
  - *guide dogs*
  - *interpreters*
  - *library readers*
  - *special classroom equipment for manually impaired*

(SS 84-43-50)

ACCESSIBILITY

All providers of education programs receiving H.E.W. funds are required to make "reasonable accommodation" to make programs, services, and facilities accessible to the handicapped.

SECTION 504 and EMPLOYMENT OF HANDICAPPED INDIVIDUALS

Discrimination in employment against qualified handicapped individuals is prohibited by SECTION 504, which states: "No qualified handicapped person shall, on the basis of handicap, be subjected to discrimination in employment under any program or activity to which this part applies". (S 84.11)

H.E.W. recipients - including programs receiving funds under P.L. 94-142 (Education for All Handicapped Children Act) are required to take Affirmative Action to employ and advance qualified handicapped persons.

DISCRIMINATION IS PROHIBITED IN:

- Recruitment
- Advertising
- Processing of applications
- Hiring, termination, and rehiring
- Upgrading, promotion and demotion
- Tenure and seniority
- Transfer
- Fringe benefits
- Layoff & return from layoff
- Rate of pay or other compensation
- Job assignment and job classification
- Organizational structure and position description
- Line of progression
- Departure and return from leave of absence and sick leave
- Selection and financial support for training including:
  - apprenticeship
  - professional meetings
  - conferences
  - leave of absence to pursue training
  - other related activities
- Employer sponsored activities including:
  - social programs
  - recreational programs
  - other terms, conditions and privileges

(S 84.11)

Employers are required to make "REASONABLE ACCOMMODATION to the known physical or mental limitations of a handicapped applicant or employee" unless they can demonstrate that this would impose an undue hardship. (S 84.12)

EMPLOYERS ARE REQUIRED TO:

- Make facilities accessible to handicapped persons
- Acquire or modify or redesign equipment or devices
- Restructure jobs
- Provide part-time or modified work schedules
- Refrain from using tests or criteria which have disproportionate, adverse effect on employment opportunities of handicapped persons

(S 84.12)

PENALTIES FOR NON-COMPLIANCE WITH SECTION 504 ARE:

"suspension or termination of or refusal to grant or to continue Federal Assistance or by any other means authorized by law". (S 80.8)

NON-COMPLIANCE COMPLAINTS SHOULD BE FILED:

- In writing within 180 days
- To HEW Regional Civil Rights Office

In Chicago: HEW REGIONAL CIVIL RIGHTS OFFICE
300 South Wacker Drive, 29th floor
Chicago, Illinois 60606
(312) 353-1781

Know Your Rights! . . . A Special Issue

REPORT FROM

CLOSER LOOK

NATIONAL INFORMATION CENTER FOR THE HANDICAPPED

A Project of the U.S. Department of Health, Education, and Welfare
Office of Education, Bureau of Education for the Handicapped

FALL 1977

You Have New Rights — Use Them!

At the beginning of this school year, some extremely important things happened which have strengthened the rights of handicapped children—and their parents.

- Final federal regulations were issued, spelling out clearly how The Education for All Handicapped Children Act (Public Law 94-142) will actually work. The regulations were published in August and went into effect October 1. They reinforce our national commitment to a free, appropriate education for every handicapped child, including the most severely disabled. And they set up detailed procedures for achieving that goal.
- Earlier in the year, in April, the federal government took action to enforce the rights of all handicapped people by setting down strong regulations for Section 504 of the Rehabilitation Act of 1973. These regulations assure equal opportunities for the handicapped in every facet of community life; in the area of education, they make clear that no handicapped child may be excluded from publicly supported schooling; that schools (including post-secondary and vocational schools) must be accessible to all; that education must meet individual needs. If a school system persists in denying the rights of the handicapped, it faces the possibility of loss of federal funding. (Section 504 prohibits discrimination against handicapped individuals of all ages by any agency or organization receiving federal funds.)

Both of these government actions have a direct impact on the lives of handicapped people—an impact which is only beginning to be felt. Both laws, strong [illegible] far-reaching as originally written, now have the [illegible]tional force of specific rules for implementation. There are, some advocates point out, certain ways in which these regulations could have been made even stronger in protecting the rights of the handicapped. But as they stand, they provide new and effective means for bringing handicapped people into the mainstream, at last.

No law is a panacea, and no law can automatically relieve parents and handicapped young people of their frustrations with systems that have only recently begun to include them. The important fact to remember is that opportunities are now available to parents that never existed before. In most cases, it's still going to take hard, persistent work—to make sure that handicapped kids get the education they need. But new opportunities are there—and parents must know how to seize them.

The recognition of the role, and the rights, of parents of handicapped children is one of the most significant changes in public policy brought about by Public Law 94-142. There is no longer any legitimate debate about whether parents should participate in planning and monitoring their child's educational program. Every step along the way—from the time a child's special need is first suspected—a parent's right to take action is now protected by law.

We've put this special issue of our newsletter together *not* to describe each specific regulation of P.L. 94-142, but to help parents use these new legal tools—and sharpen their own skills in fighting for equal opportunities for their children.

We receive letters from parents every day about school programs that are inadequate—or worse. The parents of a ten-year-old daughter born with Down's Syndrome write that she was in kindergarten for two years and a "baby-sitting" first grade for the next three

(continued on next page)

You may think we've forgotten you. We haven't. You are still on our mailing list. The fact is that the high cost of printing and distribution has made it necessary for us to combine our issues—and publish only twice each year. So, please be patient. We care about communicating with you, and you'll continue to hear from us . . . just a little less often.

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because the principal had said "she can't learn anything." A mother writes that she has battled unsuccessfully for thirteen years to get her child, who is diagnosed as having learning disabilities, out of a school "dumping ground." And the father of a teenaged boy writes in agony about years of failure. He asks urgently for some help in finding vocational education so that his son won't drown in his own defeat.

These parents now have the right to demand that their schools do something *at once* about such situations. Programs *must* be reviewed, must take into account each child's individual needs, and must contain specific, appropriate services. Individualized education programs (referred to as IEPs) must be drawn up for every handicapped child—and must be changed as children change.

By law, these programs must be designed by teams including the child's teacher, a school administrator and—you, the parent. *You belong at that conference table.* Your voice in decisions about what happens to your child in school is essential. Your instinct and knowledge about your child are invaluable—and besides, *you* are the one who has the prime responsibility for your child's welfare, not just today, but in the years to come.

This team approach is a new scenario for most people—both parents *and* professionals. We're all going to have to learn a great deal more about working together. There are many school professionals who welcome the idea of conferring with parents as equals, and see the benefits that flow from that relationship. There are others who do not welcome the idea at all, and give it lip service at best. Schools have always been *their* turf, and some of them tend to feel defensive about meetings with parents, as if they were under attack. Often, they see parents as overdemanding and pushy, or apathetic and uncooperative, not realizing that parents frequently are reacting to years of being shoved out of school offices. Many parents, on the other hand, feel shaky about contacts with the school, as if they didn't know enough to hold their own. Others may have become so angry and overbearing that they trigger hostile reactions without even realizing it. New habits of thinking and behaving are needed—not only to make meaningful planning possible, but also to open up lines of communication—so that problems can be dealt with as they come up.

This is a changing school scene, requiring more candor and open discussion, more willingness to face up to our own limitations, to recognize our own biases and see the value of pooling our thoughts and energies. What's wrong, for instance, with administrators admitting openly to parents that they must have more trained teachers and special equipment in order to serve handicapped children adequately—and then going together to the school board or state legislature, to speak up for more funding to create better programs?

It doesn't always work that way. Resistance to change is a reality. There are difficult problems, tragic problems that parents have had to live with for years. And although the law sets up machinery for solving problems through persuasion and understanding, meetings and discussions can break down. To take care of deadlocked situations, a system for settling disputes through impartial hearings is written into the law. This system for protest and appeal is going to require a lot of new learning, too. It can be cumbersome, draining and deeply frustrating.

Unquestionably, parents need help in learning the ropes. Training for parents—not just for teachers—could make things work a lot more smoothly for everyone. Advocacy organizations are taking on this assignment, and courses are springing up in how to get school services under new laws. It's a good idea; in fact, it should be a priority for every parent group. Some parent groups are beginning to set up programs for sensitizing school professionals, administrators and school board members, too, to the kinds of problems that families of handicapped children must cope with. Efforts like these can change old styles, air old grievances and possibly even bury them . . . so that we can get on with a new, fruitful collaboration between parents and professionals.

Parents are in the decision-making act now, where they belong. It may take some practice—but you can do it! In fact, this is really what hundreds of brave and forceful parents have been doing for years, as they've fought to get their kids out of inferior classrooms, insisted that children who were failing get special teaching, gone doggedly to meeting after meeting to convince schools to accept children who were considered "ineducable."

There's a difference now. A big difference. Now parents have the law on their side. If you and your child have been turned away from school, told "we don't take children like that" or given an exhausting run-around when you tried to get necessary services, this is the time to try again. (And please get the help of an experienced parent or other advocate if you possibly can!)

In the pages that follow, we've tried to be as specific as possible about some of the basic do's and don'ts of parent participation. We hope you'll find these useful. Don't forget . . . the rights of parents are there to protect the rights of children. Learn them . . . and use them!

DUE PROCESS

IN A NUTSHELL

Throughout this guide, we've indicated times when due process enters the picture. Here's a quick review to keep in mind the main steps involved in due process. Each of these steps reinforces your right to stay on top of decisions about your child.

1. You must receive notice in writing before the school system takes (or recommends) any action that may change your child's school program. Notice in writing is also required if a school refuses to take action to change your child's program.
2. You have the right to give—or withhold—permission for your child to be: tested to determine whether or not he requires special education services (identification); evaluated by specialists to determine what his educational needs are (evaluation); placed in a specific school program to meet his needs (placement).
3. You have the right to see and examine all school records related to the identification, evaluation and placement of your child. If you find that certain records are inaccurate or misleading, you have the right to ask that they be removed from your child's file. Once removed, they may *not* be used in planning for your child's placement.
4. If you do not agree with the school's course of action at *any* point along the way, you have the right to request an impartial due process hearing. This means that you can initiate a hearing to protest any decision related to identification, evaluation or placement of your child.
5. If you fail to win your case, you have the right to appeal the results of the due process hearing to the State Department of Education; and you can appeal to the courts if you lose your case at the state level.

Calling for a due process hearing is your right, but remember that it can be an exhausting process. Before going this route, be sure you have tried to settle differences through every other means—by being as persuasive as possible in meetings with teachers, the principal, special education administrators. If you know that you're up against a brick wall, and you're sure that a due process hearing must be held to resolve [illegible]licting points of view, then you must prepare your case as thoroughly as possible. Be sure to get help from an advocacy group or a lawyer who is familiar with education law and procedures in your state, or an experienced parent. (According to law, the school system must tell you about sources of free or low-cost legal aid. Ask for this information.)

Know your rights at a hearing:

- The hearing officer must be impartial, may not be employed by the school district or involved in the education of your child.
- You have the right to legal counsel (which includes the advice and support of any advocate, not necessarily a lawyer); to examine witnesses; present evidence; ask questions of school spokespeople; obtain a record of the hearing and all of its findings.

NOTE: Write directly to the superintendent of schools in your district to request a hearing. Hearings must be held not later than 45 days after requested. State Departments of Education must review appeals within 30 days.

HOW CAN CLOSER LOOK HELP YOU WITH ALL OF THIS?

We realize we're giving you lots of advice and that you may need someone to help make things happen. That's what we're here for—to help you locate people in your own area who can give that extra push. So, please write to us, and we'll do our best to boost your efforts. (When you write, it will help to tell us your child's age—and handicapping condition, if he has been diagnosed.) We'll put together as much information as we can to help you out.

If you're looking for an advocate to accompany you to a school meeting on your child's Individualized Education Program (or if you want to talk with other parents who have some know-how), it will help to contact a parent group in your community. We can give you names of organizations whose members are well-informed about federal and state laws, and the steps to follow all the way from testing to due process hearings.

If you want to read more about your child's disability, we can provide lists of books written by parents who have lived through the same trials you're facing. We will also be glad to tell you about other reading you can do about rights.

If you are uncertain about the meaning of psychological and educational testing we can give you a free booklet which can help you understand the purpose and shortcomings of the more well-known tests. (This booklet might also be helpful to your child's teacher.)

In short, we're here to help you within the limits of our resources. Let's hear from you!

Planning Your Child's Education: You Belong on the Team!

Do's and Don'ts for Parents

Laws can seem terribly formidable. It's hard to feel that they really apply to one's own son or daughter. When it comes to figuring out what they mean, our tendency is to leave it all to the "experts."

But we can't. Laws belong to us. You don't have to be a lawyer to understand a law—or to use it to change your life and your child's life.

The following *Do's and Don'ts* can help you use specific parts of The Education for All Handicapped Children Act which give parents new rights. Each of those parts relates to the ultimate goal of the law: to provide free and appropriate education services for every handicapped child. Each part interconnects with the others like pieces in a puzzle. These important pieces—*testing and evaluation, individualized education programs (IEPs) and due process*—need you, the parent, to be sure they fit together . . . and work.

None of these procedures is going to work perfectly. There are bugs in every system, and loopholes. Getting appropriate services is still going to be hard work. We hope these pointers will strengthen your hand. Not every one will apply to you; find what fits your situation, and make use of it. Good luck!

IF YOUR CHILD HAS SPECIAL NEEDS, TELL THE SCHOOL ABOUT IT!

DO . . . Get in touch with your local superintendent of schools without delay if your child has a handicap and is not in school. Your school system is obligated to find all children with disabilities. According to law, no child may be excluded from school because of a handicap. Ask that your child be given an evaluation to find out what kind of program he should have.

The school must take a careful and thorough look at any child who may need special services—by providing a comprehensive evaluation. *Once a child is found eligible for special education, the school must arrange to provide appropriate services; a meeting to prepare an individualized education program must be held within 30 days.*

Don't forget: all this applies not only to young children, but also to high school age youth with physical, mental and emotional disabilities. They are too often a forgotten population!

DO . . . Find out about preschool services for handicapped children. A great many state laws now call for special programs starting at age three, at least for certain specific disabilities. The principal of your local school (or the district superintendent) can tell you more about available programs. P.L. 94-142 provides incentives for education of children with handicaps between ages 3 and 5, and programs are growing.

DO . . . Make every effort to work with your child's classroom teacher if your child is already in school, but is having problems. There may be some discoveries you and the teacher can make together—things that can be done *right now*, during school hours or after, that can help your child. It will take thought, insight, willingness to try out suggested new activities that can add up to a brighter outlook for your youngster. Some preliminary screening may be done, too, to see if more specialized help is needed at the present time. If problems persist, don't let things slide. If you suspect that your child does have a disability *do* go ahead with procedures for getting an evaluation. (Your child's teacher, counselor or principal may carry the ball on this. If not, act on your own.)

DO . . . Remember that you can ask for a re-evaluation even if your child is already placed in a special education program. This is especially important if you feel the placement was based on old, inaccurate or incomplete tests—or if you are dissatisfied with the program. Also, it is important to keep track of a child's needs to make sure that his program continues to be really appropriate, to see if he is ready for a change, or whether his program can be improved.

DO . . . Put your request for an evaluation *in writing*—to the principal of your school or the superintendent. Keep copies of the correspondence. If vital information is discussed on the phone, write a letter confirming the gist of the conversation. Don't trust important matters (like the date, time and place of an evaluation, or what professionals are in charge of testing your child) to memory.

Due Process comes in here. You must receive a written notice from your school system asking your permission to test your child (even if you have requested the evaluation). An explanation of all your rights should be included, including your right to inspect and review all relevant school records about your child.

You must also get a notice in writing if the school turns down your request for evaluation, explaining why. If you can't get an explanation that satisfies you, and you wish to protest this decison, you can request a due process hearing at this point.

DO . . . Keep your own rights file! Use it to document any steps you take to find appropriate education and related services for your child—from the "suspicion of need" stage on up. The file should include: diagnostic test results and other professional reports, your own notations of attempts by you or your child's teacher to solve problems, reports from teachers about your child, copies of letters to and from school officials. Keep copies of state and federal laws and procedures for education of handicapped children and other relevant information. You'll need all this—to keep track of your child's progress, and to stand up for his rights if the school fails to provide an adequate program.

WHAT SHOULD YOU KNOW ABOUT TESTING AND EVALUATION?

DO . . . Be sure that the evaluation of your child is complete . . . that it does not consist only of a single test aimed at pinning an IQ score or any other label on him . . . but is a well-rounded stock-taking by a team of specialists that tells how your child is doing in all areas of his intellectual, physical and emotional development. This is the only way an *appropriate* education program can be provided. Information may be gathered in different ways . . . by talking to people who know your child (including doctors or other professionals), by conferring with classroom teachers, by meeting with you, by observing your child and giving him some tests.

DO . . . Make sure your child has a complete physical examination. This is a must. A child who is thought to be retarded may actually have a visual impairment that has never been discovered. Other difficulties may be caused by hidden physical conditions.

DO . . . Remember—calling a child handicapped by this or that condition does not tell us about his potential, how he learns best, what he *can* do.

DO . . . Talk about your own observations of your child's behavior, strengths and weaknesses to members of the evaluation team—to a guidance counselor, or social worker or school nurse. People who do the evaluating must know how a child acts and reacts with different people, in different settings, at different times . . . in school, on the playground, in his own neighborhood. Your first-hand, round-the-clock knowledge of your child is important information, and should be part of the assessment of your child's needs.

DO . . . Ask what tests will be given to your child, and why. When you sign your name giving permission to have your child tested, make your signature count. Find out what information these tests will yield that can help you and the school know how your child learns, what skills should be strengthened or developed, what problems he has to deal with, what special help he needs. Inform yourself as fully as possible about what these tests are expected to do—before giving your consent to have your child tested. (Tests may be a big mystery area for you, as they are for most people. How about making a study of testing and evaluation through your local parent group or PTA?)

DO . . . Be sure that testing does not discriminate in any way. If a child speaks Spanish, or any language other than English, tests must be given in the language he knows best. Children who have grown up in minority cultures should not be judged by answers to questions about a world that is totally strange to them. Children who are deaf must have interpreters; all testing must take the nature of handicaps into consideration, so that the picture of a child's ability is a truly fair one.

DO . . . Insist that the results of testing and evaluation be explained to you in clear, jargon-free terms, and that you have copies for your own file.

Due process comes in here. If you do not feel that the school's evaluation is fair or accurate, you are permitted by law to get an independent evaluation from other professionals. But—you may end up paying for it. The school system can ask for a due process hearing when its evaluation is challenged, to decide whether or not an outside evaluation is necessary. If the ruling is in the school's favor, the school does not have to pay. If you do get an independent evaluation (whether or not the school pays for it) it must be considered in decisions about placing your child —and it may be used as evidence in a due process hearing.

Testing will not necessarily mean that your child will be found eligible for special education. If you feel that the school's decision is wrong on this score, you can request a due process hearing at this point.

GET READY FOR MEETINGS TO DECIDE WHAT'S BEST FOR YOUR CHILD

DO . . . Be sure to attend all meetings held to plan or check into your child's individualized education program (IEP). The law states clearly that an IEP team *must* include one or both parents, the child's teacher and a representative of the school system. (Sometimes, one or more other specialists may be there, too. If this is the first time your child will get special services, someone who was involved in testing your child must be present.) Schools are expected to make every effort to get in touch with parents to make sure that they come to IEP meetings—and to arrange times that they *can* come.

IEPs must be prepared for every child who is eligible for special education. If no individualized education program has been drawn up for your child, check into it. This programming is the key to getting appropriate services.

DO . . . Prepare as well as you can for the school meeting that will design your child's educational program. Have your child's file ready, with information easily available on all testing and evaluation that has been done—by the school, or privately. Use your right to go through school records to be sure they are accurate and up-to-date. This meeting *must* be based on a recent and comprehensive evaluation, so check to be absolutely sure this has happened.

DO . . . Bring along a helper to the IEP meeting, if you will feel more comfortable or secure. More and more people are getting special training to act as advocates

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for parents in these new and unfamiliar circumstances. Your helper can rehearse with you ahead of time, explain what will go on and how decisions about the IEP will be reached. Ask members of your local parent organization if they are aware of this kind of help. If you can't find someone trained as an advocate, try to get assistance from another parent who has been through it. Experience is a great teacher, and you can benefit from it.

DO . . . Be as clear as possible in your own mind about what kind of things you believe your child is ready to learn. Talk these over with professionals you trust, and rely on your own knowledge of your child, too. Make a checklist of key items. Does your son need to learn to sit still and listen, instead of interrupting constantly or making inappropriate comments? Does your daughter need to learn how to speak distinctly? Does she need help with self-care skills? Is your teenager getting pre-vocational or job-skill training?

DO . . . Be able to back up your requests for special kinds of help with diagnostic reports, observations and other information from professionals who know your child. If you wish, you may ask to have professionals accompany you to support your point of view. This is your right according to law.

DO . . . Remember—diagnostic reports, important as they are, are not infallible. They don't say *all* there is to be said about a child. Your most important job is to make sure that the others at the conference never forget that you're talking about a real child—not scores attained on a series of psychological tests. Bring up all the real-life information you feel is relevant to a discussion about your son or daughter's educational needs. In the past, there was far too much tendency to rely on reports and records, not to look at the child himself. This is your chance to push for this change in perspective.

DO . . . Be wary of any suggestion to place your child (or leave him) in a classroom that has a label. The old approach was to give children "trainable retarded education" or "blind education" or "physically handicapped education" which more often than not meant inferior education, or none at all. That's what the new law is supposed to stop. The program your child gets should be built on services that relate to strengths and abilities, special problems and learning needs . . . not to his category of disability. If you don't agree that this is what the program does, speak up for your point of view—and make sure that changes are made.

DO . . . Try to understand the issue of "mainstreaming" as fully as possible. The law is based on the right of handicapped children to be part of the world, to learn, work and play alongside their non-handicapped schoolmates. The law's words for it are: educating children in the "least restrictive environment." Somebody coined the word "mainstreaming" to describe this view and the term stuck. Whatever words you use, it makes a big difference in the image that children have of themselves, their confidence and their ability to get along as accepted members of society. This doesn't mean that *every* handicapped child belongs in a regular class. But he *should* be given that chance, if with sufficient aid and understanding, he can hold his own. And if a child spends all day in a separate class because his need for small classes is so great, he should be given every possible opportunity to join his peers in other school activities. This is an essential part of his education.

DO . . . Take some time to think about how to be assertive without "taking over" or antagonizing people. Meetings about a child's school needs are not intended to be hostile confrontations; they should provide the chance for honest examination of alternatives. One way to keep it successful is to realize you *do* have an essential role to play as an equal-status member of the team—along with educators. Keep calm, listen to what the others have to say, and ask them to extend the same courtesy to you. Your points of view may be new to each other, and you may disagree, but you can learn from one another. If everyone is truly concerned about giving a child the chance he needs to grow and learn, it should be possible to iron out disagreements through persuasion and mutual understanding.

DO . . . Make sure that your child is not excluded from participating in a regular school program because of architectural barriers. This is against the law. Sectio 504 states very clearly that school facilities must be made accessible and that special adaptations must be made so that services are really available to all students.

STUDY THE FINAL IEP BEFORE GIVING YOUR CONSENT—AND INSIST ON ESSENTIAL SERVICES

DO . . . Have a very complete understanding of the IEP that is produced. A copy of the final IEP should be given to you in writing. Make sure that the education goals that are agreed on are specific and that they accurately reflect decisions that were made at the meeting.

An IEP should *not* contain general goals, like: "Maximize child's potential," but should include clear-cut objectives that can be measured. One objective, for instance, could be: to be able to identify a specific number of words by sight within a certain period of time. Long term goals such as reading at a first grade level should be included, too—so you know where you're going.

An IEP should also say how much time a child is t spend in the mainstream, either in regular classes o extra-curricular activities. Services to be given should be clearly defined. For instance, if speech therapy is in the IEP, how often will it take place? What kinds of activities will it include? When will it start? How long will it go on? How will progress be charted? If other supportive services, such as transportation or hearing aids are needed, this should be in writing, too.

Check the whole thing carefully—with people who can advise you. The better you know and understand the IEP, the better you will be able to follow your child's progress, monitor the program to see if it is effective, and ask for changes or modifications when necessary.

DO . . . Make sure that appropriate vocational education is in your son or daughter's IEP. This has been a terribly neglected area; insist that work-skill training, on-the-job experience and other skills related to independent living are built into the school program provided for your teenager—as needed. There may not even be a vocational education program for handicapped students in your school system. (You may have to work hard with administrators and teachers to get one started. But speaking up about the need, making sure it's in the IEP, is a first step.)

DO . . . Be firm about things you consider important. Although you don't want to be so rigid that no possible plan could ever get off the ground, you *are* the main protector of your child's interests. If the proposed program segregates your child in a separate classroom all day, and you are convinced that he should have the chance to make it in a regular school activity (at least part of the day), stick to your guns. If a specific classroom or school has been recommended, visit it—to see if it really meets your child's needs. Art, music, school plays, gym, shop are part of the school day for other kids. Your handicapped child should be included. This will require modifications in the way programs are offered—but it can be done!

Due process comes in here. Parents must give their consent to placement of their child. If you feel that an essential part of the program is omitted, is harmful to your child, or is truly inappropriate, you should make your objections known. If the school system is not able to provide the kind of educational program your child must have, it is responsible, by law, for financing an appropriate education in a private facility. This can be a difficult bone of contention, and requires detailed evidence. In all controversies, you must put together documents, reports, letters and other statements (from teachers, doctors, and other specialists who know your child) to support your view. If possible, meet with the school members of the IEP team again to present your side. If you reach a dead end and are unable to convince school officials to change the program or placement, then ask for a due process hearing at this point. While controversial issues are being decided, children must be permitted to remain in their present school setting.

FOLLOW YOUR CHILD'S PROGRAM AND MAKE SURE IT'S WORKING.

DO . . . Get to know the teacher, once your child is placed. Ask when he or she would like to meet with you. Regular conferences are important—to find out how your child is doing, to bring up questions you have, to discuss any possible new efforts at school or at home. A good, trusting relationship between you and the teacher can catch a lot of problems before they get too big to manage.

DO . . . Help teachers and other people in school learn more about handicaps. You can help overcome feelings of fear and pity that come from lack of experience. Share books and articles. If possible, arrange for your child's teacher to visit with your son or daughter before school starts (or after school some day) so he or she has a chance to get a feeling for your child's personal qualities. (The extra boost to their relationship will help them both survive later problems—if they arise.) Offer to talk to other parents in the class—so they in turn can help *their* children accept and understand differences . . . and make friends. You want your child to become independent—but it won't help him to have to deal with unnecessary fear or aggression based on ignorance.

DO . . . Make sure that a formal evaluation of your child's program takes place every year . . . at the very least. If you stay in close touch with the classroom teacher (and other specialists who work with your child), you'll be able to know if changes should take place sooner—and will certainly be able to play a more meaningful part in planning next steps. Making sure that a program continues to be appropriate requires vigilant checking and rechecking . . . to see if school placement is actually encouraging a child's growth.

DO . . . Listen to your child, respect what he's saying. You need to know his reaction to schoolwork, to teachers, to classmates. He may need help getting "toughened up" in the real school world. If you are worried about how things are going . . . again, talk to the teacher, or the school counselor or principal, for advice and suggestions. Keep all your lines of communication open.

BUT PLEASE . . .

DON'T . . . let other people plan for you. If, for instance, you have reason to think that school people met "behind the scenes" to agree on the IEP, effectively keeping you out of the act, you have grounds to complain loudly. Some school administrators have had nothing but difficult experiences with parents and they freeze at the thought of working with them. (It works the other way around, too. You may have had so many frustrating or intimidating experiences that you don't want to try again. Please do.) You and the school *can* work together. Don't let the potential for a new creative process die by default.

DON'T . . . settle for poor or inadequate services. If you find that your child's problems are ignored, that special resource teachers or educational materials don't exist, that your child is deprived of assistance he

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Do's and Dont's *(continued)*

needs to adjust to a mainstreamed classroom in which he has been placed . . . take action. Demand changes in keeping with the promise of an appropriate program.

Due process comes in here. If your efforts to work with your child's teacher, principal or school administrators fail, you have a right to request a due process hearing at this point in order to protest your child's placement.

DON'T . . . let yourself feel put down at the meetings held to discuss, plan or evaluate your child's program. It may sound scary at first, but it really doesn't have to be. When professionals use language you don't understand, feel free to ask for explanations. Remember that you are all there for the same purpose: to work out what's best for your child . . . to pinpoint his needs and to make decisions on what resources, services and special programs he needs in order to learn. You can make a valuable contribution by raising questions when ideas and recommendations don't seem to make sense.

DON'T . . . forget that, no matter how important every educational service provided to your child may be, he is a young, responsive, growing individual, with human needs to laugh, play, make friends—not a composite of diagnosed needs. The brightness of social success means as much as academic progress (sometimes, it can mean even more). This side of life can be overlooked in conscientious efforts to improve learning skills. Your handicapped child is person—and the purpose of all these efforts is to help him use his own strengths to become the most fulfilled person he can be. That's why it's so important to give each kid as much chance as possible to join the mainstream and to be part of the fun activities of school.

DON'T . . . try to do this all alone. Join with other parents in an organization for handicapped individuals, or the PTA, to learn all you can about new federal and state laws, the way your own school system works, how to stick up for your rights. There's so much to do! You're not the only one who needs help. Find your allies—and work together. If teaching programs for handicapped children are below standard, and none of your efforts to bring about improvement have worked, you will be far more effective if you become part of an organized group. You can add strength to a broader effort to implement and strengthen existing laws, to push for increased funding by state legislatures, to awaken the rest of the community to the rights of handicapped children.

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YOUR CHILD'S SCHOOL RECORDS

When children are enrolled in school, a large number of records are developed on such items as their academic performance and program, health needs, and discipline. These records can help you to determine whether your child needs special education services. If they contain outdated or inaccurate information, it can result in your child receiving inappropriate services - or no services at all. For these reasons, you should familiarize yourself with the contents of your child's file.

School officials are also required to notify you about your rights concerning your child's school records. Your child's school is required to establish written procedures to carry out these rights.

Your right to inspect your child's records and your right to confidentiality as to their contents are guaranteed under:

- The Illinois School Student Records Act (Article 50, THE SCHOOL CODE OF ILLINOIS)
- The U.S. Family Educational Rights and Privacy Act of 1974
- P.L.94-142 The Education for All Handicapped Children Act
- Section 504 of the Rehabilitation Act of 1973

YOU HAVE THE RIGHT TO:

- Examine all information contained in your child's school records. This includes:
  - reports and other information sent to your child's school by hospitals, clinics, private doctors and other professionals
  - all other information maintained by the school concerning your child (This does not include personal notes of school staffpersons, as long as the note is not shared with other persons)
- Receive an explanation of the contents by a qualified professional
- Challenge the contents of the record (excluding grades) asking for correction or deletion of inaccurate, misleading or inappropriate data, or insert into the records a written explanation of your own about the contents
- Confidentiality of the contents of the records
- Obtain copies of your child's records
- Designate, in writing, persons who may have access to your child's school records
- Have your request to examine the records granted within 15 days
- Be notified annually of: the types of records maintained by the district, the names of persons who are responsible for these records, the location of the records, retention and destruction schedules, persons having access to the records without your consent, that information designated "directory information" and your rights under the law and procedures for exercising these rights

NO INFORMATION CONTAINED IN YOUR CHILD"S RECORDS CAN BE RELEASED WITHOUT YOUR WRITTEN PERMISSION EXCEPT:

- To a parent of the student, your designated representative, or a person having your specific, dated, written consent

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- To the official records custodian of another school, within or outside of Illinois in which the student has enrolled or intends to enroll, upon the request of the student or school records custodian.

- For research purposes or statistical reporting or planning, with the consent of the State Superintendent of Education and provided no parent or student can be identified from the information released.

- Pursuant to a court order, you must be given prompt, written notice of the terms of the order, the information to be released, and the opportunity to inspect, copy, and challenge this information

- In an emergency where knowledge of such information is necessary to protect the health or safety of the student or other persons.

- As specifically required by state or federal law.

- Information classified as "directory information".

THE ABOVE RIGHTS APPLY TO:

- Public schools
- State institutions
- Handicapped students who have been placed in a nonpublic special education facility under the provision of Section 14-7.02 of The School Code of Illinois

You can still have access to your child's records or challenge their contents even if your child is no longer in attendance at the school or institution.

WHEN YOUR CHILD REACHES THE AGE OF 16, MARRIES, ENTERS THE MILITARY, OR ENROLLS IN A POST-SECONDARY EDUCATION PROGRAM, HE/SHE ASSUMES THE RIGHTS HIS/HER PARENTS FORMERLY HAD. He/she then has the right to the access and release of school records; and the parents no longer have this right except by written permission of the child.

YOU SHOULD REVIEW YOUR CHILD'S SCHOOL RECORDS ANNUALLY:
- Before he/she transfers to another school
- Before participating in a special education conference
- Before participating in a special education impartial due process hearing

PROCEDURES
Contact your child's school principal and request to see all of your child's school records. Illinois law requires that the records be made available to you within 15 school days of your request.
IF ANY OF THE ABOVE RIGHTS ARE DENIED YOU... You have the right to:

- File a complaint with your Regional Superintendent (SESR) and then the Office of Student Affairs, Illinois State Board of Education, 100 N. First St., Springfield, Ill. 62777. (217) 782-9546
- Initiate a Due Process Hearing.
- Initiate Action for injunctive relief or an action for damages in the Circuit Court of the County in which the violation took place or in the county in which the school is located.
- File a written complaint with:

The Family Educational Rights and Privacy Act Office
Dept. of Health, Education, and Welfare
330 Independence Avenue, S.W., Washington, DC 20201

A. Content of the IEP

What is the content of the individualized education program (IEP)?

According to Section 121a.346 of Title 45, Public Welfare, the IEP must include:

1. A statement of the child's present levels of educational performance;
2. A statement of annual goals, including short-term instructional objectives;
3. A statement of the specific special education and related services to be provided to the child, and the extent to which the child will be able to participate in regular educational programs;
4. The projected dates for initiation of services and the anticipated duration of the services; and
5. Appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short-term instructional objectives are being achieved.

1. *A Statement of the Child's Present Levels of Educational Performance*

The level of educational performance on the initial IEP should be based on data derived from the multi-factored evaluation. Subsequent IEP revisions should use the most current data to describe the present levels of educational performance.

aThe type of data included in the statement of the child's present levels of educational performance should reflect those areas for which special education intervention is being considered. The following represents areas of functioning which are commonly evaluated when considering special education placement; academic achievement levels, communication skills, prevocational and vocational skills, daily living skills, social and emotional adjustment. The type and number of areas may vary for each child.

2. *A Statement of Annual Goals, Including Short-Term Instructional Objectives*

How is an annual goal defined?

Ohio Standards for Special Education (3301-51-18: A.b. [ii] [a]) define annual goal as:

. . . a statement of the expected behavior to be achieved within a calendar year through the implementation of the child's individualized education program.

One of the significant steps in determining the need for a special education program for a child is to examine the reasons that the child was referred as a suspected handicapped child. An examination of the reasons for referral should identify areas, either academic, social, behavioral, or vocational, that caused a teacher or parent to suspect a need for special education. These identified needs should have been utilized in determining the evaluation procedures and instruments. The results of the evaluation should reflect specific instructional needs to assure an appropriate educational opportunity for the child. It would appear that an annual goal should be developed for each of the major needs identified in the evaluation and placement procedures.

How is a short-term instructional objective defined?

Ohio Standards for Special Education (3301-51-18: A.b. [ii] [b]) define a short-term instructional objective as:

. . . an intermediate step in the accomplishment of the stated annual goals.

For each annual goal, one or more short-term instructional objectives must be identified. The number of short-term instructional objectives developed depends upon the annual goal.

Specific criteria may be added to each of the objectives since the regulations require appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short-term instructional objectives are being achieved.

In summary, the key concepts concerning short-term instructional objectives are (a) that they must be related to the annual goals since they are the intermediate steps and (b) that there must be some criteria identified so that the achievement of each of the objectives can be determined on at least an annual basis.

The regulations specify only the content of the IEP; they do not specify the form or format that must be used. As long as the IEP is developed in a meeting with the appropriate participants, and a complete copy is provided to the parent, a checklist could be used as an attachment to the IEP form.

3. *A Statement of the Specific Special Education and Related Services To Be Provided to the Child, and the Extent to which the Child will be Able to Participate in Regular Educational Programs*

From: The Least Restrictive Environment and the Handicapped Student Aids for the Regular Classroom Teacher, by Marsha Schubert, Harriet Glick, Deborah Bauer, Wright State University Special Education - LRE Project, Dayton, OH 454 35.

Must the special education personnel write goals and objectives for those areas in which the child is participating with nonhandicapped children in the regular education program?

The regulations require that the extent of participation in the regular education program be identified as a part of the IEP. The regulations further state that annual goals and short-term instructional objectives be developed for those *special education and related services* that are identified in the individualized education program. There is no requirement that goals and objectives be developed for those areas in which the child is participating with nonhandicapped in the regular education program.

Physical education services, specifically designed if necessary, must be made available to every handicapped child receiving a free, appropriate public education.

Under Part B, Free Appropriate Public Education (FAPE) means special education and related services . . . which are provided in conformity with an IEP. The timelines for FAPE are the same for both Part B and Section 504. Read together, these two statutes and their implementing regulations require that by September 1, 1978, each handicapped child must be provided all services necessary to meet his/her special education and related needs.

4. *The Projected Dates for Initiation of Services and the Anticipated Duration of the Services*

Since the IEP is a written statement developed for each handicapped child, the anticipated duration of special education programs and related services must be determined for each child. This statement of duration should represent the best estimate of how long the child will require these special education programs and related services. It is not meant to be a binding statement since it is reviewed at least annually, and can be revised at any appropriate time. It could be anticipated that some children may need the special education program throughout their entire school career while others may need it only during the elementary school years and still others may need it for only one year, or less.

5. *Appropriate Objective Criteria and Evaluation Procedures and Schedules for Determining, on at least an Annual Basis, Whether the Short-Term Instructional Objectives are being Achieved*

Is the teacher liable if the student does not achieve the objectives as stated in the IEP?

Section 121a.349 of Title 45, Public Welfare, states:

Each public agency must provide special education and related services to a handicapped child in accordance with an individualized education program. However, Part B of the Act does not require that any agency, teacher, or other person be held accountable if a child does not achieve the growth projected in the annual goals and objectives.

B. Development of the IEP

1. *Required IEP Meetings*

An individualized education program must be in effect before special education and related services are provided to a child.

Each public agency shall initiate and conduct meetings to periodically review each child's individualized education program and if appropriate revise its provisions. A meeting must be held for this purpose at least once a year.

The IEP can be revised at any time, provided appropriate notice is given the parents and the meeting is conducted with the necessary participants.

The IEP need not be on file in the classroom; however, it must be easily accessible to all personnel delivering the special education and related services.

2. *Participants in IEP Meetings*

Who must participate in the development of the individualized education program (IEP)?

In accordance with Section 121a.344, of Title 45, Public Welfare, the participants in the development of the IEP must include:

(a) General

The public agency shall insure that each meeting includes the following participants:

1. A representative of the public agency, other than the child's teacher, who is qualified to provide, or supervise the provision of special education.
2. The child's teacher.
3. One or both of the child's parents, subject to 121a.345.
4. The child, where appropriate.
5. Other individuals at the discretion of the parent or agency.

(b) Evaluation personnel

For a handicapped child who has been evaluated for the first time, the public agency shall insure:

1. That a member of the evaluation team participates in the meeting; or
2. That the representative of the public agency, the child's teacher, or some other person is present at the meeting, who is knowledgable about the evaluation procedures used with the child and is familiar with the results of the evaluation.

Pine Local School District

INDIVIDUALIZED EDUCATION PROGRAM

Student's Name: *Albert Hays* **Date of Birth:** *6/17/62*

Current Placement: *EMR Special Education Classroom* **School:** *Richards High School*

I. Present Levels of Educational Performance: (Areas - social adaptation, emotional maturity, prevocational and vocational skills, activities of daily living, academic achievement, communication skills and other areas identified in multi-factored evaluations).

a) Adaptive Behavior - can read a bus schedule and is familiar with city streets.

b) Vocational/occupational needs - is able to use newspaper for finding help-wanted ads - is able to complete a job application.

c) Academic functioning - has vocabulary level of 5.5 - can write phrases, incomplete sentences.

d) Communication skills - Percentage of time sounds produced accurately: /S/12%, /Z/10%, /L/40%, /R/60% - passed screen hearing test - normal oral peripheral examination.

II. List Special Education Services

Programs	Date Initiated	Anticipated Duration	Related Services	Date Initiated	Anticipated Duration	Extent of Participation in Regular Education
Special EMR class	*9/11/78*	*High School*	*Work-study*	*9/11/78*	*High School*	*Home Room*
			Speech therapy	*10/11/78*	*2 years*	*Physical Education*
						Industrial Arts

Participants in IEP Meeting

III.

Date	Signatures	Title
9/8/78	Diane Climent	Member of Evaluation Team
9/8/78	Chad Bright	Rep. of School District
9/8/78	Francis Drey	Teacher
9/8/78	Penelope Hays	Parent
		Other

IV. Schedule for Evaluation and Periodic Review of Short-term Instructional Objectives September, 1979

V. Annual Goals and Short-term Instructional Objectives

	Goal	Objectives	Criteria and Evaluation Procedures	
a)	Correct production of S, Z, L & R sounds.	1. Produce correct S, Z & L sounds through the stages of isolation, syllables, words, phrases in a therapy setting.	90%	Reading aloud
		2. Produce correct R sound through the stages of isolation, syllables, words, phrases, sentences in a therapy setting.		
b)	The student will write complete sentences.	1. Student will write sentences which contain subjects and predicates	75%	Pre-post testing
		2. Student will capitalize beginning words and proper nouns with 75% accuracy.		
		3. Student will use question mark and period with 75% accuracy.		
c)	Student will use city bus system without getting lost.	1. Will use a bus schedule.	Reaching destination	Performance task
		2. Student will travel by bus between destinations without getting lost.		
d)	Student will develop skills in interviewing for a job.	1. Student will complete an in-school interview successfully, as determined by the interviewer.	80%	Checklist
		2. Complete application and interview at BES.		
		3. Complete interview with employer successfully as determined by interview.		

IEP Resource Booklet. Columbus, Ohio: Ohio Department of Education, Division of Special Education 1979

Coordinating Council for Handicapped Children
LET'S MAKE WAVES
407 S. DEARBORN STREET · Room 680 · CHICAGO, IL 60605 · (312) 939-3513

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How To Be Assertive At Your Child's IEP

> *" At my child's IEP meeting, I was handed an IEP which was already all written up and I was told to sign it."*

YOU HAVE THE RIGHT TO BE ASSERTIVE AND PARTICIPATE IN THE DEVELOPMENT OF YOUR CHILD'S IEP , AND FILE FOR A DUE PROCESS HEARING IF YOU DON'T AGREE.

Learn to use the IEP (Individualized Education Program) process as an effective tool to obtain appropriate special education and related services for your child.

P.L.94-142 (The Education for ALL Handicapped Children Act) mandates that a free appropriate education must be provided to all handicapped children ages 3 to 21. The IEP is the specific guidelines for your child's appropriate education. As a parent you are an important member of the team that formulates your child's IEP. You should know:

- how to prepare for an IEP meeting
- how to write your own IEP statement
- how to effectively represent your child at an IEP meeting
- how to deal with negative comments and criticism
- how to obtain appropriate special education and related services for your child

WHAT IS AN IEP?

P.L.94-142 (the Education for All Handicapped Children Act) guarantees a parent's right to participate in the planning of her child's IEP. You must always keep in mind that, as the parent, you know your child better than anyone else. Professionals may be the experts on current theories and educational practices, but you, the parent, are the expert on what has been occurring with your child on a day to day basis from the time he/she was born.

According to federal law, you must be notified of the date selected for the IEP meeting, time, location, purpose, and who will be in attendance. You are also entitled to ask that the meeting be rescheduled at a mutually convenient time, if you are unable to attend on the preselected date.

Before attending the IEP meeting, it is useful to review your child's school records. P.L. 94-142, and the Illinois Student Record Act of 1975 ensure's a parent's right to examine school records, to receive an explanation of the contents, to challenge the contents of the records, and to obtain copies of the records. (See Chapter 18, HOW TO GET SERVICES BY BEING ASSERTIVE.)

The IEP must state the specific special education services your child will need. For Example: one hour resource room daily; self-contained classroom for the autistic, using simultaneous communication, intrusion, relationship and behavior therapy. The extent of your child's participation in the regular education program should be stated, also. For Example: attendance in a regular social studies class, physical education class, and art class.

According to P.L.94-142, necessary transportation services and vehicle adaptation must be included in the IEP.

The meeting should begin with a report of your child's present level of functioning. His/her weaknesses and strengths should be discussed. From this the professionals (usually the teacher) and the parent(s) together should formulate the annual goals for the coming year, and the short-term instructional objectives for the immediate future (the next two to three months).

AN ANNUAL GOAL IS A GENERAL STATEMENT OF DESIRED CHANGE AND PROGRESS TO BE WORKED TOWARDS THROUGHOUT THE YEAR. FOR EXAMPLE: to improve self-help skills, to eliminate self-destructive behavior, to improve understanding of basic math concepts. The number of annual goals is determined by the nature and severity of the handicap. Generally, there are about five.

A SHORT-TERM INSTRUCTIONAL OBJECTIVE IS A SPECIFIC STATEMENT REGARDING CHANGES AND PROGRESS TO BE ACHIEVED DURING THE NEXT TWO TO THREE MONTHS. This is to include the materials and methods that will be utilized, how often, and for how many minutes the objective will be worked on; also, what criteria and evaluation procedures will be used to determine to what extent each goal has been achieved.

(1) FOR EXAMPLE: TO TEACH THE CHILD HOW TO BUTTON HER COAT. The child will be required to attempt to button her coat before leaving the school on a daily basis. The teacher will assist the child, only after the child attempts to do it herself. The teacher will reward the child with praise for trying. The child will also work with a big button doll for 3 minutes, 3 times a week with assistance and verbal reinforcements from the teacher. Criteria for completion of the goal will be the ability to button the coat independently 90% of the time.

(2) FOR EXAMPLE: TO ACHIEVE UNDERSTANDING OF ADDITION IN ONE DIGIT EQUATIONS. One-to-one assistance for 10 minutes each day using math Level 1 flash cards, supplemented by the Level 1 workbook for 10 minutes daily; ten minutes of small group (4 to 5) math work using the board will be provided daily. A homework assignment of 5 math problems to be monitored by the parents will be given 3 times a week. The criteria for completion of the goal will be on an 85% correct score on weekly review tests.

YOUR CHILD IS ENTITLED TO RELATED SERVICES - that is, developmental, corrective, and other supportive services - that are required to assist a handicapped student benefit from special education . The need for related services is determined by appropriate evaluation of the child's needs.

If you feel your child is in need of a specific related service, such as speech therapy, occupational therapy, physical therapy, recreation, counselling, etc., you should request an evaluation of that specific area.

The IEP should state each needed related service, the date of initiation of the service, and the anticipated duration of the service. It should also state how many times a week, and for how many minutes the service will be rendered, and by whom.

FOR EXAMPLE: SPEECH THERAPY FOR 20 MINUTES, THREE TIMES A WEEK; PHYSICAL THERAPY FOR 20 MINUTES DAILY.

When requesting needed related services, base your request on the premise that your child needs a given service in order to benefit from his/her educational program. If you feel that the recommendation for the related service by the school personnel does not accurately reflect the needs of your child, you may seek an outside evaluation.

Resources may be available in your community, or through a state agency at low cost or no cost to you. You may also be able to use your medical insurance to pay for a portion of the needed evaluation. You are entitled to obtain an independent evaluation at public expense if there is a ruling by a Due Process Hearing that the district's evaluation was not appropriate.

FOR EXAMPLE, YOU MAY FEEL YOUR CHILD NEEDS OCCUPATIONAL THERAPY. The school evaluates your child, and the recommendation is - no occupational therapy needed. You suspect that your child does need occupational therapy, but you know that your school does not employ an occupational therapist at this time. Therefore, you are unsure of the objectivity of its evaluation.

SEEK AN OUTSIDE EVALUATION, AND OBTAIN A RECOMMENDATION. If you get a recommendation for occupational therapy, request a conference to amend the IEP. Present your outside evaluation. If the school refuses to accept the results of the outside evaluation, file for a Due Process Hearing immediately.

(The above procedure can be followed when your child is receiving a needed related service, but the amount of time alloted for that service is inadequate.)

BEFORE THE IEP MEETING

1. Obtain a copy of the Federal Rules and Regulations on P.L.94-142 and your State Rules and Regulations. You can request a copy from the public school; the school is required to supply parents with a copy upon request. (However, many public schools are not aware of this, and do not have a supply of the Rules and Regulations) Read pertinent portions, underline the most significant sections, and make your own index. Use the language of the Rules and Regulations to represent your child. For example, avoid using the phrase "most appropriate " or the phrase "best educational environment".

50

Appropriate is the key word, and will enable you to represent your position adequately. Adding other words may open the door to word games that will only deflect from the focus of the meeting - - which is, an appropriate educational program for your child.

2. Prepare a written statement of your input for the IEP meeting. Make enough copies to pass out to all in attendance. Read the statement out loud. This will insure that all your concerns will be heard. Your statement should simply state the services, goals, and objectives you feel are appropriate for your child. You do not need to write the complete IEP, nor do you need to stipulate what types of materials will be used (unless you have a real preference). This should be done at the meeting. Your main objective is to present your views on your child's educational needs. (See a sample IEP on page 5.)

AT THE MEETING

1 Do not go to the IEP meeting alone, It is common for parents to feel overwhelmed and alone when confronted with a room full of professionals discussing their child in a clinical manner. Invite other parents, friends, relatives, and anyone you know who might be interested in attending. Explain to them that you would like them to attend to give you moral support, and to function as witnesses in case of a disagreement.

2. The image you portray will effect how the school personnel react towards you. If you wish to be treated in a professional manner, you should dress in a professional manner. Choose clothing that is simple but dignified. Walk into the room with confidence. Don't wait to be acknowledged, but introduce yourself and begin greeting people as soon as you enter the room. Bring your copy of the Rules and Regulations with you and display it prominently on the table. Remember that it is your taxpayers'money that is paying for the salaries of the school personnel. They are working FOR you and your child.

3. It is a good business procedure to tape record the meeting. It will not be possible to take accurate notes in this situation, and personal notes can be disputed. Simply place the recorder on the table and plug it in. (Don't ask for permission) If someone expresses resistance, explain to them that it is a good business procedure to tape important meetings, such as this IEP meeting.

4. Pass around a sign-in sheet at the beginning of the meeting. You will then have the names of all those present, and be able to address them by name, (from their positions on the sign-up sheet) whom you are speaking to.

5. Follow all steps in Chapter 29, HOW TO GET SERVICES BY BEING ASSERTIVE.

6. When speaking during the meeting, take a deep breath to help project your voice clearly and confidently. Maintain eye contact with the professionals while you speak.

7. When negative comments are made about you and your child, use these remarks to build your case for needed services for your child. (See Chapter 25.

8. Repeat what you are asking for whenever school personnel offer excuses or evasions. Remember that you are not there to discuss the limitations of the school budget. You are there to determine what your child needs to have an appropriate education. State this repeatedly, as often as necessary to make your point. (See Chapter 22, HOW TO GET SERVICES BY BEING ASSERTIVE.)

9. If school personnel state that there is a certain policy, rule, regulation, or law that requires them to take certain action or not to take certain action, do not feel intimidated. Ask to see in writing the specific policy, rule, regulation or law that they are referring to. Remember that federal law, and rules and regulations take precedence over state and local policies, laws, rules, and regulations.

IF YOU DO NOT AGREE

1. If you cannot come to an agreement, and you are running out of time. Or if you feel you need time to consider the situation, you have the right to request another meeting. Do not feel pressured to make a decision.

2. Most schools ask that you sign the IEP form. However, federal and state law do not require that you sign the IEP. If you don't agree, simply sign your attendance at the IEP meeting to document your presence. Specify that you are not in approval of the present IEP. For example: Anna Jones, present, but not in approval of IEP.

If school personnel refuse to include needed services in the IEP, inform them that you intend to file for a due process hearing and that you will file a written complaint with the Office of Civil Rights, Dept. of Health, Education, and Welfare, and write the Bureau of Education for the Handicapped.

Be sure to ask for a copy of the IEP. The IEP may be revised at anytime if you so request. It must be reviewed annually.

SAMPLE PARENT IEP STATEMENT:

PARENTAL INPUT ON THE INDIVIDUALIZED EDUCATION PROGRAM FOR JAMIE GREEN

- Placement in a class of 4 to 6 students with a teacher who is skilled in play therapy, intrusion therapy, consistency, and positive reinforcements. The teacher and the teacher's aid must be proficient in sign language.

- It is crucial that Jamie have contact with signing peers who can function as role models on a daily basis.

LONG TERM GOALS

- Increase in relating and socializing abilities.
- Increase in communication skills
- Improvement in self-help and survival skills
- Development of prevocational skills

SHORT-TERM INSTRUCTIONAL OBJECTIVES

- To increase relating and socializing abilities; intrusion/play therapy, using simultaneous communication should be provided for 30 minutes, 3 times a week on a one-to-one basis. Doll play, tickling, picture book sign language stories, etc., should be utilized.

- To increase communication skills; art therapy, utilizing drawing, should be used on a one-to-one basis for 20 minutes, daily. Jamie expresses herself through her drawings more so than through any other means.

- To improve self-help and survival skills: 40 minutes daily should be spent on activities such as washing dishes, bathing, and crossing the street.

- To develop prevocational skills: crafts should be used for 45 minutes, 3 times a week. The curriculum should include macrame, pottery, weaving, and basket weaving.

INTRODUCING THREE BOOKS NO PARENT OR PROFESSIONAL SHOULD BE WITHOUT

HOW TO GET SERVICES BY BEING ASSERTIVE will show you how to build self-confidence, improve you communication, and negotiating skills, cut red tape and move bureaucratic mountains, and much more. Available for $4, plus 60¢ postage.

HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES will show you how to be an effective advocate, an effective organizer, how to negotiate for better services, how to lobby, and much more. Available for $4, plus 60¢ postage.

THE DIRECTORY OF SERVICES FOR HANDICAPPED CHILDREN AND ADULTS is a spiral bound 311-page REDBOOK, listing 1,571 resources for the handicapped from birth through adulthood in the Chicago metropolitan area, both alphabetically and by disability group with charts of services. Available for $10, plus $1.50 postage and handling.

RECEIVE CONTINUOUS UP-TO-DATE INFORMATION ON SPECIAL EDUCATION, NATIONAL AND STATE LEGISLATION. JOIN THE COORDINATING COUNCIL FOR HANDICAPPED CHILDREN. MEMBERSHIP: IND./FAM. $10___ CONTRIBUTOR $15___ ORGANIZATION $30___ LIFETIME $100 (IND./FAM. ONLY)___ NEWSLETTER SUBSCRIPTION ONLY $8___

NAME______________________________ PHONE__________

ADDRESS__________________ CITY__________ STATE______ ZIP__________

You will receive a monthly newsletter and other educational materials and literature. Mail your tax deductible check to CCHC, 407 S. Dearborn, Rm. 680, Chicago, Il. 60605.

HOW TO PREPARE FOR A DUE PROCESS HEARING

WHAT IS A DUE PROCESS HEARING?

If you disagree with the proposed IEP: if you are dissatisfied with the child's present placement; or if you feel you have been denied any of your rights -- you have the right to an IMPARTIAL DUE PROCESS HEARING. An Impartial Due Process Hearing is a special hearing set by the Illinois Office of Education, where an impartial hearing officer hears both sides and renders a decision to the local education agency.

Your request for a hearing must be made in writing to your public school district superintendent. If you wish to challenge the placement of your child, your request for a hearing must be made within 10 school days of your receipt of notification of the proposed placement. Within 5 school days of your request for a hearing, the local school district will schedule a conference to review the case. Your participation and the participation of representatives of your choosing, will be an important part of this conference.

If the controversy cannot be resolved at this conference, a due process hearing will be scheduled. A certified letter requesting the appointment of an impartial hearing officer will be sent immediately to the Illinois Office of Education, with a copy to the parents.

The hearing will be scheduled by the Hearing Officer at a time which is convenient to you and to representatives of your choosing (a lawyer, an advocate, another parent).

Your child will remain in his present program until the hearing has been held and a decision has been rendered.

The state appointed hearing officer's recommendation will be communicated to you, in writing, by certified mail within 10 school days after the hearing.

If you are not satisfied with the result of the hearing, you have the right to request a state-level review. You also have the right to appeal to the courts after other levels of appeal and communication have been exhausted.

BEFORE THE HEARING

1. BE AWARE OF YOUR RIGHTS. Find out what you are legally entitled to for your child in special education and related services, and the resources you have BY LAW if you are dissatisfied with a placement or proposed placement. YOUR RIGHTS ARE SPECIFIED IN P.L. 94-142; Rules and Regulations on P.L. 94-142; the School Code of Illinois, Article 14; the State Rules and Regulations to Govern the Administration and Operation of Special Education; The Family Rights and Privacy Act of 1974; The Illinois School Records Act; and Section 504 of the Rehabilitation Act of 1973.

   FEDERAL legislation listed above is available from: U.S. Office of Education Donahoe Building, 400 - 6th St., S.W., Washington, DC 20202.

Copied with the consent of COORDINATING COUNCIL FOR HANDICAPPED CHILDREN

ILLINOIS legislation listed above is available from: Illinois Office of Education, 100 North First Street, Springfield, Il. 62777

2. READ AND CAREFULLY STUDY ALL MATERIAL IN #1 ABOVE. Study the material as if you were taking an exam on it. Underline and mark the material as you study.

   Especially underline and mark all the material that applies to your case.

3. VISIT THE PROGRAM THAT THE SCHOOL DISTRICT HAS OFFERED (which you feel is not appropriate for your child). Spend a whole day if you can. Take a notebook along and take notes that will help you document why the program is not an appropriate one for your child.

4. USE CCHC'S CHECK LIST-EVALUATION FORM FOR PUBLIC AND PRIVATE DAY SCHOOLS FOR THE HANDICAPPED to help you evaluate the program.

5. INSPECT YOUR CHILD'S SCHOOL RECORDS. State and federal law gives you the right to:

   a. examine all information contained in your child's school records
   b. challenge the content of the records
   c. ask for correction or deletion of any inaccurate, misleading or inappropriate data
   d. insert into the records a written explanation of your own about the contents
   e. privacy as to the contents of the records
   f. obtain copies of your child's records at cost
   g. designate, in writing, a person who may have access to your child's records
   h. have your request to examine records granted within 15 school days.

6. OBTAIN AN OUTSIDE EVALUATION - If you haven't one already - at a reputable hospital or clinic which has a certified school psychologist on the staff. An evaluation by a reputable hospital or clinic will carry more weight than one done by a private physician, psychologist, psychiatrist, or neurologist.

7. OBTAIN A LETTER - ADDRESSED TO YOU - FROM THE HOSPITAL OR CLINIC which performed the evaluation, documenting why the proposed placement is not appropriate for your child, and making specific recommendations for a placement which agrees with your placement plan.

8. REHEARSE YOUR PRESENTATION. Try and anticipate all arguments that may be presented by school officials opposing your demands - and rehearse appropriate responses. (See p. 3 for a sample of arguments and appropriate responses.)

AT THE HEARING

1. BRING all material from #1 ABOVE TO THE HEARING, and display it on the table for everyone to see. (This will let everyone know you know your rights.) Be sure you have appropriate markers so that you can locate the information you need easily.

2. BRING RESULTS OF EVALUATIONS, LETTERS FROM PROFESSIONALS, AND ALL OTHER DATA DOCUMENTING THAT THE PROGRAM OFFERED IS NOT APPROPRIATE FOR YOUR CHILD.

3. BRING YOUR OWN REPRESENTATIVES TO THE HEARING, as you are entitled to by law. These can be:

   a. a professional who has evaluated your child
   b. a lawyer
   c. another parent, parent group representative, or advocate
   d. a community representative
   e. a friend or a relative

4. AN INTERPRETER MUST BE PROVIDED if you are hearing impaired or if the language of your home is other than English.

5. A TYPEWRITTEN RECORD BY A COURT REPORTER OR A TAPE WITH TYPEWRITTEN TRANSCRIPT MUST BE MADE. You may receive a copy of the record upon request, at cost. You should also bring your own tape recorder, so that you have your own record of the hearing.

REMEMBER

THE IMAGE YOU PROJECT AND THE ATTITUDE YOU COMMUNICATE WILL PROBABLY INFLUENCE THE OUTCOME OF THE HEARING. It's important to communicate in a business-like manner and convey the message that you are informed and aware of your rights. Be positive and self-confident. An attitude that conveys the message that you expect to lose will not help you win.

TRUE-FALSE TEST REGARDING PUBLIC LAW 94-142

INSTRUCTIONS: *Carefully read each of the following 10 statements and then indicate whether or not you believe the item to be true by circling either "True" or "False."*

1. Public Law 94-142 Regulations provide for Free Appropriate Public Education to all handicapped youth who need special education. TRUE FALSE
2. P.L. 94-142 Regulations require each handicapped child be educated with nonhandicapped children. TRUE FALSE
3. P.L. 94-142 Regulations state that an Individualized Education Program (IEP) must be in effect before special education can be provided to a child. TRUE FALSE
4. P.L. 94-142 Regulations state that a child's Individualized Education Program must cover all academic areas. TRUE FALSE
5. P.L. 94-142 Regulations provide a standard method for writing Individualized Education Programs that must be met by each state. TRUE FALSE
6. P.L. 94-142 Regulations state that if parents, after being notified, choose not to participate in the development of their child's Individualized Education Program, a school district can proceed without them. TRUE FALSE
7. P.L. 94-142 Regulations require states to provide professional and support staff with in-service training in special education. TRUE FALSE
8. P.L. 94-142 Regulations state that teachers will not be held accountable if a child does not reach his/her annual goals and objectives. TRUE FALSE
9. P.L. 94-142 Regulations allow a parent or public education agency to make an appeal if dissatisfied with the results of a due process hearing. TRUE FALSE
10. Under P.L. 94-142 Regulations, both states and school districts are entitled to federal funds based, in part, on a formula concerned with the number of children between the ages of 3 and 21 who actually receive special education and related services. TRUE FALSE

KEY: 1.(T) 2.(F) 3.(T) 4.(F) 5.(F) 6.(T) 7.(T) 8.(T) 9.(T) 10.(T)

From: Clarification of PL 94-142 for the Paraprofessional and Support Staff by Research for Better Schools, Inc., Philadelphia, July 1980.

SEC. 504 - 1973 REHABILITATION ACT AND AMENDMENTS AND 1975 EDUCATION ACT FOR ALL HANDICAPPED CHILDREN (P.L. 94-142)

Public Law 94-142 and Section 504 - Understanding What They Are and Are Not

1977. 1 to 9 copies, 50¢ each. 10 or more copies, 40¢ each. Send order with remittance to The Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091. pp. 12 and appendix.

This is probably best single clear and concise of all the references I have seen on this subject. A "must" for every administrator.

Section 504 of the Rehabilitation Act of 1973 Fact Sheet: Handicapped Persons Rights under Federal Law

March 1978. Free. See page 2 "Program Accessibility" especially and pages 7 and 8 for various compliance dates. Write Hew Office for Civil Rights, Washington, D.C. 20201. pp. 10 pamphlet.

Exceptionally good brief summary to hand to anyone seeking these specific items of information.

The Rehabilitation Act: An Analysis of the Section 504 Regulations and Its Implications for State and Local Educational Agencies

1977. $2.50. National Association of State Directors of Special Education, Inc., 101-16th Street, N.W., Washington, D.C. 20036. (202) 833-4193. pp. 12. paperback.

This is a book which I just received a week ago. It is EXCELLENT. It is a perfect companion piece for Item 1 listed on this bibliography.

An Analysis of P.L. 94-142.

No date given. $2.50. National Association of State Directors of Special Education, Inc., 1201-16th Street, N.W., Washington, D.C. 20036. pp.26. Spiral notebook.

This is a predecessor to item 3 above but is not nearly as good as the revision.

"Programs for the Handicapped bimonthly". See January/February 1979 issues. Number 1. See pp. 6 and 7 re: Comprehensive Employment and Training Act Amendments of 1978 (P.L. 95-524) and note second paragraph on p. 7 beginning "Section 306 ...." possible labor help for removing physical barriers in schools.

Write Office For Handicapped Individuals, DHEW, Washington, D.C. 20201 to get your name on the regular mailing list for all issues of this reference newsletter type of publication. You will have to ask specifically for the copy I mentioned above in order to get it now.

Section 504: Self-Evaluation Guide: Preschool Elementary, Secondary and Adult Education. Civil Rights-Handicapped Persons-and Education.

August 1978. Free. Write to James Bennett, Office for Civil Rights, 330 Independence Avenue S.W., Washington, D.C. 20201. pp. 116.

This is one of the most helpful books you will find anywhere on Sec. 504 and the levels of education above. See pp. 59-96 and pp. 97-105 particularly Subpart D. Free Appropriate Public Education and Rating Scale.

A MUST FOR EVERYONE IN EDUCATION!

UNIT II: RIGHTS & ROLES

GOALS AND OBJECTIVES

Roles and Responsibilities of Allied Health Professionals

Purpose:

To have participants explore their roles and responsibilities in identifying, referring and advocating on behalf of disabled children and youth.

Specific Objectives:

At the conclusion of this session, participants will have identified the roles and responsibilities of Allied Health Professionals with respect to the needs and rights of disabled children and youth.

In addition, the participants should:

1. Recognize the need to be sensitive to parents', siblings', and child/youth's verbal and nonverbal cues which indicate concerns/problems related to a handicapping condition.
2. Recognize the need to be sensitive to and understand the influence of cultural differences in the identification and referral processes.
3. Recognize prevalent forms of prejudice and stereotyping, and understand how myths and stereotypes contribute to the devaluation of people with handicapping conditions.

ROLES AND RESPONSIBILITIES OF ALLIED HEALTH PROFESSIONALS AS IDENTIFIED BY REGION V PARTICIPANTS

1. To communicate effectively with disabled children and youth and their families; i.e., to effectively adapt messages and actively listen to disabled children and their families.

2. To help families solve problems related to the disabled child/youth's condition; that is

   a. To facilitate children/youth receiving appropriate services, and
   b. To facilitate parents becoming child/youth's case manager.

3. To recognize the indicators of handicapping conditions for severe, mild-moderate, and high-risk children and youth.

4. To recognize and accept the needs and rights of disabled youngsters.

5. To understand and be able to implement methods for identifying appropriate referral sources.

6. To help coordinate efforts of health, education, and related services:

   a. To understand other health, education, and related services professionals' roles;
   b. To work cooperatively with other professionals concerned with the services provided for disabled children and youth, and to actively participate in coordinated and appropriate health-care planning; and
   c. To communicate effectively with other professionals on behalf of children and youth with disabilities.

7. To develop effective alliances between various professional organizations and existing parent professional coalitions.

8. To develop and provide cost-effective model programs and services.

9. To recognize and provide accurate information to parents.

10. To assist parents in defining their roles and rights.

11. To promote self-advocacy skills.

12. To be sensitive to and to cooperate in the development of adaptive programming during the life span of the disabled child.

13. To understand and be able to explain to parents the effect of current treatments on the future performance of the child.

14. To advocate for appropriate research.

15. To disseminate accurate information to the public concerning:

    a. the nature of the disabling conditions;
    b. the needs of the disabled;
    c. the roles Allied Health professionals play in the rehabilitation of disabled individuals; and
    d. qualifications for providing services.

16. To identify and help implement more creative approaches to funding programs for disabled youngsters.

17. To develop and/or modify educational standards to create access rather than barriers to disabled individuals who wish to enter Allied Health educational programs.

18. To encourage the development of pilot projects to prepare individuals of disabling conditions to enter the Allied Health professions.

In addition, the Allied Health Professional should:

19. Recognize the need to be sensitive to parents', siblings', and child/youth's verbal and nonverbal cues which indicate concerns/problems related to a handicapping condition.

20. Recognize the need to be sensitive to and understand the influence of cultural differences in the identification and referral processes.

21. Recognize prevalent forms of prejudice and stereotyping, and understand how myths and stereotypes contribute to the devaluation of people with handicapping conditions.

UNIT II: RIGHTS & ROLES

RESOURCES

- The American Family, Report No. 4: Why Did It Happen To Us? A Psychiatrist Explores Chronic Childhood Disability in the Family by Dane G. Prugh, M.D. A Continuing Education Service from Smith, Kline & French Laboratories.
- Handicapism, by Robert Bogdan and Douglas Biklen. Printed in Social Policy, March/April 1977, pp. 14-19.
- Media Portrayals of Disabled People: A Study in Stererotypes, by Douglas Biklen and Robert Bogdan.
- What Is Mainstreaming, from Mainstreaming Preschoolers by the Head Start Bureau.
- About Disabilities - from the book: What's the Difference? Teaching Positive Attitudes Toward People with Disabilities, by Ellen Barnes, Carol Berrigan and Douglas Biklen.
- Fact Sheet: Being at Ease with Handicapped Children, by ERIC Clearinghouse for Handicapped and Gifted Children, Reston, VA. 22091.
- Professional Disciplines: Roles & Responsibilities, by Sylvia Richardson, M.D. from AAP "New Directions in Care for the Handicapped Child".
- Information ... CLOSER LOOK...
  Into The Mainstream
- Bibliography - to include Publications List from Regional Rehabilitation Research Institute on Attitudinal, Legal and Leisure Barriers.

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Report Number 4

THE
AMERICAN
FAMILY

WHY DID IT HAPPEN TO US?

A Psychiatrist Explores Chronic Childhood Disability in the Family

by Dane G. Prugh, M.D.

A Continuing Education Service from
Smith Kline &French
Laboratories
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"The American Family"

This article [illegible] the contemporary American family. Here, Dr. [illegible] Prugh provides [illegible] of the effects of [illegible] childhood [illegible] the child and the [illegible]

"The American Family" [illegible] Smith Kline & French Laboratories [illegible] Israel Zwerling, M.D., Ph.D., Professor and Chairman, Department of Mental Health Sciences, Hahnemann Medical College and Hospital, Philadelphia.

We welcome [illegible] suggestions [illegible] "The American Family," Department E90, Smith Kline & French Laboratories, P.O. Box 7929, Philadelphia, PA 19101.

About the Author

[illegible]

Moderator's Comments

[illegible] the patient's response to [illegible] In this paper [illegible] the relationship between the [illegible] child and the family. He has drawn on his extensive experience [illegible] and a child [illegible]

Israel Zwerling

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WHY DID IT HAPPEN TO US?

A Psychiatrist Explores Chronic Childhood Disability in the Family

by Dane G. Prugh, M.D.

A chronic disability in childhood can be said to be a disorder (illness or handicap) that is protracted, sometimes with exacerbations, and is associated with some impairment of function and interference with development. It is not necessarily permanent, and may be compatible with a fairly normal life-span. Certain disorders, however, may progress to a fatal outcome. Chronic handicap may be congenital or acquired; some disorders in each category may be reversed or repaired, and these may or may not be permanent. The onset of chronic illness or handicap may be related to an acute catastrophic illness or injury, or may have been gradual and insidious.

Although serious repercussions on the child's personality development and on the nature of family functioning are frequent, many children with chronic illness or with congenital or acquired handicaps make a surprisingly adequate adaptation to or compensation for their disabilities. Those variables relating to the child's previous adaptive capacity and the parent-child-family balance or interpersonal equilibrium appear to be more important than the nature of the specific disease or handicap.[12,15] The child's state of development, the severity of the illness or handicap, the prognosis, the nature of necessary treatment, and other factors are, of course, also significant.

Special challenges to development exist for children with blindness or deafness, with some differences in responses to congenital vs. acquired defects. Problems in sexual development are present for children with pseudohermaphroditism or exstrophy of the bladder. Difficulties in adaptation arise for the young child whose movements are restrained in an orthopedic cast or who requires special prosthetic devices. The debilitation and discomfort produced by certain diseases certainly have an effect on the child's social or academic functioning and on the parents' responses.

The response of both children and parents to the disability depends on many factors. The earlier concept of specific personality malformations resulting from particular chronic illness or handicaps has today been largely abandoned. Personality disorders encountered in children with a variety of chronic illnesses or handicaps resemble closely those seen in children with no physical disorder. The fear of loss of control of the environment in the blind child, the apprehension over losing balance and falling in those with cerebral palsy, and the suspicion of what is being said about themselves by the deaf are frequently present, but do not appear unique to those disorders.

Even a small and virtually unnoticeable defect may carry overwhelming significance in certain families for unconsciously overdetermined reasons. Although visible cosmetic defects may be most troubling in some families, in others a hidden metabolic defect may be more mysterious and threatening, without relation to its actual severity. The source of the threat lies more often in the psychosocial rather than the biological determinants of the responses of families to illness in children.

The Social Field of Illness

The concept of the social field of illness includes both the effect of interpersonal forces on the child's adaptive equilibrium, with reverberations at the psychological and physiological levels, and the impact of the child's predominantly physical illness on the most important social unit—the family. A child's illness may bring about a family crisis. Families with healthy adaptive patterns may respond with behavior leading to a new and different family adaptive equilibrium, representing a type of family development. In less well-balanced families, parental patterns of

In seriously disturbed families, the child who falls ill may be made a scapegoat for family tensions....

handling the ill child may be significantly altered because of more than usual anxiety or guilt, causing further changes in the behavior of the child or occasioning rivalrous or other responses in siblings. In seriously disturbed families, the child who falls ill may be made a scapegoat for family tensions, may be treated unrealistically as a chronic invalid, or may be handled in other ways that reflect the unconscious tendency of the parents or other family members to respond to his illness in terms of their own needs rather than his. Families from differing socioeconomic and ethnic backgrounds may respond quite differently to the illness of a child and may react positively or negatively to the need for dependence on medical personnel or other helping agencies.

The importance of all these considerations renders it vital that the clinician accept the *family* rather than the individual as the essential unit for the study and treatment of disease. The illness of a child with acute or chronic disease both affects and is affected by the interpersonal family equilibrium in the particular community, society, and culture.

The reactions discussed below may occur with any illness. They are largely nonspecific responses related to the way in which the environment—parental, familial, social, and physical—helps the child deal with the physical consequences and the symbolic meaning of illness or injury. Frequently, such responses can also be seen in children encountering psychological or social stresses. They are principally situational or reactive disorders, although continuing developmental deviations, structured psychoneurotic disorders, chronic personality disorders, or even psychotic disorders may be touched off or exacerbated by such stresses in biologically or experientially disposed children.

Phasic Responses

Within broad limits, however, the nature of the illness and its attendant treatment are of significant influence. This is particularly true in catastrophic or overwhelming types of illness or injury. In such situations, there is a generic type of human response related to the adaptive mechanisms involved in the handling of the phases of impact, recoil, and restitution. Such phasic responses may be seen most clearly in children of school age and beyond.[13] Although preschool children tend to show similar patterns, they are less clear-cut.

With serious burns, spinal cord injuries, and respiratory polio, the phase of impact involves initial realistic fears, followed by marked regression, sweeping denial, and the use of primitive fantasy. The phase of recoil includes a lessening of regression and denial, and the use of primitive fantasy. This phase includes a further lessening of regression and features the "mourning for the loss of the self that was to be." The child may need to test out persons around him to see if he is still likable. Depression may occur, warded off for a time by eating disturbances or hostile, demanding behavior. The phase of restitution permits the start of adaptation to and attempts at mastery of the situation, during which individual patterns related to premorbid personality trends emerge. If residual illness or handicap remains, the way in which these phases are negotiated may influence long-term adjustment.

Within the family equilibrium, specific reactions of parents to serious or disabling illness tend to parallel the phasic responses in children. Initial realistic fear is often followed, as Garrard and Richmond[5] have indicated, by: (1) a phase of denial and disbelief, persisting for weeks or, at times, months; (2) fear and frustration, involving "mourning for the loss of the child that was to be." This phase may be associated with depression, guilt, and self-recrimination, with intensified marital strife (a high rate of divorce is associated with the attempt of many parents to deal with such feelings by blaming themselves, the physician, or others); (3) rational inquiry and planning, involving the need to live with some uncertainty.

Whether a child's illness or injury produces a deleterious effect on his adaptation or the family's equilibrium depends on: (1) the developmental level of the child; (2) the child's previous adaptive capacity; (3) the prior nature of the parent-child relationship; (4) the existing family equilibrium; (5) the nature of the illness or injury, including the organ system affected, the degree of prostration or pain, the type of treatment or home care, and any residual defect or handicap; (6) the meaning of the illness to the child and his family in terms of immediately antecedent events and their

In disorders with a genetic component, children may blame a parent or relative who has a similar disorder for having "given" it to them.

actual or fantasied connection to the illness, the previous experience with such illness, the effect on the child's social, academic, and athletic capacities, and the reverberations on siblings; (7) the capacity of the family to acknowledge the child's devotion to and concern for the other members of the family; and (8) the strength or weakness of the extended family or the kinship network, especially with regard to relationships with grandparents.

Reactions of Children and Adolescents

The concept of coping behavior is important in understanding the reaction of children and adolescents to chronic disability. As Mattsson[11] has emphasized, coping behavior involves all the adaptive mechanisms employed by the child to master stressful stimuli at the physical, psychological, and social levels of organization of his personality—thus including cognitive behavior, emotional expression, psychological defenses and motor activity. If coping behavior is successful, adaptation is achieved, with the child functioning effectively whatever the nature or degree of his disability.

The direct effects of chronic illness or handicap include malaise, discomfort, and pain from the disorder itself or attendant treatment, feelings of fatigue and irritability, as well as the effects of any physical limitations. Reactive effects include regression, particularly in the early phases; depression; misinterpretation of the cause or treatment procedures as punishment, especially in young children; physiological concomitants of anxiety, which may compound the effects of the illness; conversion reactions; and dissociative reactions.

In young children, other responses center around resentment or complaints about interruption of play to take medicines or other treatments, dietary restrictions, and any physical limitations that prevent them from keeping up with others. As with acute illness, young preschool children are most concerned with separation from parents. Late preschool and early school-age children are more concerned with the conditions surrounding the illness or treatment procedures; they tend to misinterpret pain or other symptoms as punishment for disobedience or other minor transgressions. Children with heart disease may explain their disability as the result of having been too active, while those with diabetes may believe they have eaten too many sweets. In disorders with a genetic component, children may blame a parent or relative who has a similar disorder for having "given" it to them. (Reactions to the experience of hospitalization and treatment in a hospital setting will be discussed later.)

School-age children may become frustrated and anxious over lack of information about their condition, or frightened by conflicting information, especially if the parents cannot discuss the facts with them because of their own feelings. They may worry about death from a serious condition, although death is not comprehended realistically until nine or ten years of age. They are, however, sensitive to the agony of their parents.

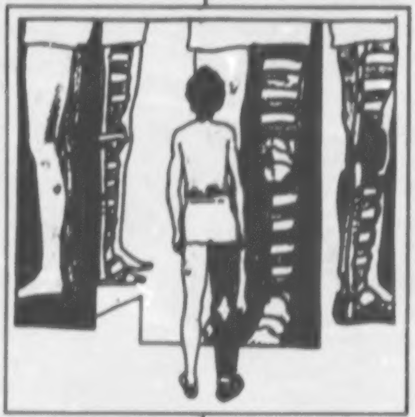
Late school-age children and adolescents may worry especially about the restrictions imposed upon their social life and their developing identity, and may be particularly sensitive to "teasing" or other evidence of lack of acceptance by their peers. They may hide their feelings of inadequacy, inferiority, discouragement, helplessness, and depression, as well as recurring thoughts about "never growing up" to be a man or woman, or their fears of death. Adolescents especially may be ashamed of their illness because of particular limitations or embarrassing symptoms. They are often deeply concerned about its possible effects on their educational and vocational plans, and on the possibilities of marriage and parenthood.

Emotional immaturity, overdependence, social inhibitions and other neurotic symptoms, pseudoindependence, learning difficulties, rebellious behavior at home and at school, and resistance to therapy may be encountered in some older school-age children and adolescents. Conversion symptoms may be interwoven with basically physical symptoms of a chronic disorder, intensifying the disability, sometimes to a serious degree. Conversion mechanisms or other psychological responses, such as depression or school phobia, may lead to invalidism in only slightly handicapped children; for this reason, homebound teachers, though helpful, should be used sparingly. The acute phase of a chronic disorder may evoke a reactive disorder; the chronic phase may result in developmental deviations in motor, social, or other dimensions. In some cases, a structured psychoneurotic or personality disorder may be associated with a chronic illness or handicap, or, more rarely, decompensation may ensue,

Difficulties in the establishment or maintenance of the body image...are present for most children with a chronic illness or handicap.

with the appearance of a psychotic disorder.

One of the common results of a chronic disorder with associated impairment in functioning is a limitation in the experience of the child, particularly in regard to social activities. With less opportunity for positive feedback from others, he may fail to develop adequate self-esteem, and his motivation for learning or for achievement in other ways may be detrimentally affected. Since there may be a discrepancy between his aspirations and his capacities, it is often very difficult for the child with a chronic disorder to develop goal-directed behavior or realistic long-term goals.



Effects on Body Image

Difficulties in the establishment or maintenance of the body image, or the mind's picture of the body, are present for most children with a chronic illness or handicap. Such problems, however, may also be seen in children with psychosocial difficulties without physical limitations or disfigurement; healthy children, too, may have confusion about their bodies.[6] Thus, children with chronic conditions (and acute as well) may easily become confused and anxious about the effects of medical or surgical procedures on vital organs, such as on the heart; from abdominal paracentesis; or on the genitals, from procedures carried out in the inguinal region. Size, strength, and attractiveness do play some role in the child's confidence and social adjustment, but only in very special cases or in individual family situations do these factors appear to be of prime importance.

Other factors are of course involved. The stage of development is important; cosmetic defects in facial or other visible body parts present special problems for adolescents, particularly as MacGregor[10] has shown. The development of intimate heterosexual relationships by an adolescent with a chronic disability may be a special difficulty,[2] and problems in adaptation often appear during adolescence in children whose earlier coping has been fairly successful. Depression, marked denial, or other responses to a damaged body image may interfere with the acceptance of rehabilitative procedures during the late preschool period, when the body image of a male or female is being formed. Social or interpersonal factors may also be significant.[3] Difficulties may arise in individual adolescents struggling with identity problems, if their limitations or defects are significantly different from other adolescents being treated for the same basic disorder. Some may feel too "different," while others may feel guilty if they have less extensive damage or defect than the majority of the group.

Even the nature of treatment may influence the body image.[13] Unfortunately, there has been too little concern in the medical profession, including among many psychiatrists, with body image problems in illness. The clinician should be aware of what a changed body means to a patient, giving due recognition to the importance of "somatopsychic" factors. Encouraging a child to talk about the meaning of his illness or injury, including his concerns about changes in his body image, should form a part of the supportive psychological components of total therapy in the acute as well as chronic phases of the disorder. It would seem clear that children and adolescents with chronic illnesses or handicaps must mourn again at each stage of development, with differing implications, the lost "self."

Reactions of Parents and Families

Even if the onset of a serious illness or handicap is gradual, rather than catastrophic, parents tend to go through the same phases. The initial fear is related to possible fatal outcome associated with shock, resentment, or anger, and denial and disbelief of the diagnosis and its long-term implications. Complaints of incomplete information and "shopping around" for other opinions may accompany this phase. As the parents move into the phase of fear and frustration, in which they begin to accept the reality of the chronic disorder and to mourn, feelings of guilt over having failed to prevent the disorder or of having transmitted or somehow caused it are experienced. Blame may be projected onto medical or nursing staff or onto the spouse. Serious depression of one or both parents can occur. When the parents can verbalize and cope with such feelings they can move into the phase of rational inquiry and planning, and are ready to accept the reality and impact of the serious disorder.

During the course of the chronic condition, even parents

Blame may be projected onto medical or nursing staff or onto the spouse.

who have successfully negotiated the initial phasic responses may encounter significant problems, however, in the face of the very real stresses involved, including financial burdens, physical strain or fatigue, discouragement, emotional depletion, and the necessary rearrangement of family patterns of living. At each stage of the child's development, parents also need to mourn again.

One of the central difficulties for parents of children with chronic disorders is the handling of the dependence-independence dimension of child-rearing. Some younger children tend to cling to dependency for security, and their parents may have difficulty in encouraging the child to "move out" physically, socially, and academically within realistic limits. Others may try to push the child toward unrealistic independence, with the child clinging or at times defiant in response. Most parents also have difficulty in talking with the child about his condition, and some may even hide the facts from him. Difficulties in communication may occur between the parents also; a father may be unable to talk about the child's disorder and may give the child's care to the mother while staying away from the situation. Parental overprotectiveness in this regard may limit the child's ability to show concern to the parents.

Parents may differ between themselves in their perceptions of the child's limitations or capacities. This may lead to the situation where one parent pushes and the other protects the child, with consequent serious marital battles. This is especially true if marital disagreements have been present prior to the onset of the child's disorder. The result of such battles in families of children with chronic disorders may be divorce. Some parents search ceaselessly and make unrealistic sacrifices for new and hopefully miraculous treatments; they may also resent the child's failure to be grateful for such strenuous self-sacrifices, developing ambivalent feelings toward him as a result. This tends to contribute strongly to a sense of guilt over imagined disloyalty to the parents in a sick child.

Although such problems occur, a surprisingly large group of parents can adapt successfully to the problems involved in rearing a chronically ill or handicapped child. Such parents can, after the initial phases of response, come to understand and accept the child's limitations; they can permit dependence within limits while helping the child move toward appropriate independence and self-care. They can encourage regular school attendance, and can guide the child in developing compensatory physical and intellectual activities. Such parents see that only the most necessary restrictions are placed upon the child, and that he has opportunities for adequate social and recreational experiences.

Parents who have successfully adapted in this way usually rear children who can successfully cope. In coping with the continuing strain of the situation, however, they tend to use some denial in dealing with an uncertain future and in maintaining hope. Denial and isolation of feelings of helplessness and anxiety may also be employed during an exacerbation of the child's illness or other medical crisis, although as Mattsson[11] has indicated, they may experience later a "rebound phenomenon" involving feelings of depression or irritability. Rationalization is another common defense. Some parents may feel that the child's disability has helped the whole family (which may be true but may help also to ward off too strongly feelings of sadness or resentment). Many parents also use intellectual methods of coping, by reading material or attending lectures dealing with the medical or psychological aspects of their children's disorders. Identification with other parents whose children have similar disabilities can be of positive value to many, though not all, parents, and a number can benefit from being able to help other parents who are beginning to face a similar experience.

Maladaptive patterns of parents also fall along a continuum. The largest group tend to be overanxious, overprotective, and overindulgent, with difficulties in setting limits on the child's demands. These parents usually have been unable to deal successfully with feelings of guilt about failing to "protect" the child from becoming sick or disabled, transmitting the disorder to the child if the disorder is known to have hereditary components, or not wanting the child originally. At times the illness or injury reactivates parental conflicts related to the death of a relative, or the child may have experienced a serious illness at birth or in infancy from which he was not expected to recover. Temperamental differences, the developmental stage at which the disorder appears, and other factors may help to determine the child's response to these parental patterns.

At the other end of the continuum is a much smaller

In some families, any social stigma attached to the child's disorder...may be felt so keenly by the parents that they may unconsciously isolate the child within the family.

group of parents who have been unable to accept the child's disability. They experience the same feelings of guilt and resentment over their child's disorder, but react differently from the first group because of their personality patterns, previous experiences, marital conflicts, or other factors. This group may deny the extent of the child's disorder and may push him beyond his capacities. A few parents may need to deny the child's illness because of irrational fears that he may die suddenly, no matter what the cause of the illness, fears that may be transmitted to the child. Others in this group may project the blame for the child's difficulties with his disorder onto the medical staff, and may postpone seeking help, may be reluctant to accept recommendations for treatment, or may unconsciously "forget" them. Some of these parents may unconsciously perceive the child's defect as reflecting their own, based on past feelings of inadequacy or guilt, or as representing "retribution" for their own past transgressions. They may unconsciously wish the child had not survived, to stand as a visible reflection of their own limitations.

In some families, any social stigma attached to the child's disorder, as with epilepsy, may be felt so keenly by the parents that they may unconsciously isolate the child within the family. Lack of knowledge about the etiology of the disorder may contribute to such behavior, as may cultural beliefs about the "evil eye." The roots are usually deeper, however, and often reflect some conflicts about this particular child prior to the onset of the condition. Some families may go to the extreme of isolating themselves from social interactions, while others may engage in a battle with society over the child's disorder and its implications. A few parents may blame the child for causing them inconvenience, or may openly reject or neglect the child. Children reared by such parents may become either overly responsible out of guilt, depressed and hopeless, or angry and rebellious. In either case, the child's feelings may interfere with self-care or response to treatment. The sick child thus may behave as if he were the parent of his parents.

Reactions of Siblings

In certain families, one parent (most often but not always the mother) may out of unconscious needs devote so much time to the care of the child with the chronic disorder that the siblings may feel left out or neglected. Occasionally the parent will "devote her life" to the care of the ill child because of marital conflict or a "need to be needed," with the result that the siblings and even the husband are actually neglected. Situations of this kind may lead to jealous and demanding behavior, open complaints, aggressive or destructive behavior, psychophysiological disorders, or learning difficulties, among others. Younger siblings may even pretend to have the same illness, while older children and adolescents may develop similar conversion symptoms. Young preschool children may be expected to understand the handicapped child's problems before they are capable of doing so, at a time when they have a great need for affection themselves. Children and adolescents may become "too good" out of guilt over being well, or may develop overly self-sacrificing attitudes and behavior. Resentment and other responses are common and intense in families that tend to avoid open discussion of feelings of any kind. An open acknowledgment of the contributions of the siblings to the ability of the family to cope with the difficulty may relieve some of their burdens.

Initial Management of Chronic Illness or Handicap

The approach to management begins with the onset of the disorder, whether catastrophic or gradual in nature. The way in which the child and family are helped to pass through the phases of impact and recoil, with adequate grief reactions, and to begin the process of restitution, with the acceptance of change and with appropriate inquiry and planning, will help to determine the nature of the long-term adaptation. The management of psychophysiological disorders, which may produce states of chronic illness or handicap, involves some special considerations,[12] as does the handling of the parents' initial response to the birth of an infant with a congenital abnormality.

A study carried out in the Child Development Department of the Institute of Education in London strongly suggests that the earlier the parents of children with Down's syndrome are told of their child's condition the better are their long-term acceptance and adjustment. Seriously

When one asks the child what is the most difficult thing about his illness, one can often get valuable clues that can lead to significantly supportive measures.

damaged and profoundly retarded children may have to be placed in an institution, although medical group foster homes are better (though few). The majority of retarded children are mildly retarded (50-70 IQ), and should be kept at home if possible with support for the parents. They can learn to read, write, work, and live independently, and most do not give birth to retarded children. A large number of these are retarded only because of sociocultural deprivation. Many retarded children develop emotional problems because of parents' guilt or hopelessness on the part of parents and teachers; these can be treated, and special vocational programs can be most effective. Too often the striking devotion of these children and their roles in caring for other family members is not acknowledged.

The Approach to the Child

It is important that the physician interview the child alone in order to give him or her an opportunity to ask questions and to air misconceptions that may negatively affect the self-image. These may include the fear that the illness represents punishment, that he or she will not grow up to be a man or woman, or some of the other confusions about body image mentioned earlier. Only by understanding the patient's own thoughts, feelings, and fears about the condition can the physician or health associate offer focused rather than blanket reassurances, and make sure he understands the condition as fully as possible. As Levy[9] has pointed out, some of these feelings may be expressed during the course of the physical examination, as the result of judicious questions about the child's feelings about the illness, the ways his body functions, and his ideas about why he is sick. If the young person shows resistance to treatment, only open discussion of his feelings about treatment procedures, his condition and his future outlook, and his parents' reaction can be of significant help. With adolescents, it is valuable to discuss the problem also in a family interview in order to promote open and supportive communication about the handling of the condition. As a general rule, the professional caretaker should avoid an alliance with the child behind the backs of the parents.

Again, the training and experience of most physicians or other health professionals often militate against discussing a child's chronic condition on the grounds that the child may become discouraged or depressed if forced to think about the implications for his future. On the contrary, most older children and adolescents are preoccupied with such thoughts, and an opportunity to discuss them and provide accurate medical information can only be beneficial. The chance to ventilate frustrations, fears, discouragement, and resentment is usually eagerly seized upon and, after discussion, the reality of the future is often more positive than the uncertainty of his fears. Also, one can sometimes learn from the child himself facts about his illness or his family situation which did not come to light in the parents' history.

When one asks the child what is the most difficult thing about his illness, one can often get valuable clues that can lead to significantly supportive measures. If he says the kids tease him at school, one can give emotional support but can also contact the teacher to help him or her to understand the illness and to communicate such understanding to the patient's fellow students. If a child with hemophilia says that his disorder was caused by his "running around too much," one can reassure him specifically that it was not his fault, but can also deal with his parents' guilt and help them discuss the reality of the situation with him. Here, the use of figure drawings can be helpful in understanding the child's body image or feelings about himself, his illness, or his family's response.[17]

By asking a child, up to early adolescence, for "three wishes," "Would you like to get married and have children?" or "Tell me about a good (or bad) dream," one can ordinarily get very quickly a helpful picture of a child's feelings about himself, his family, and his illness. In general, if the child has a physical illness, his first wish will be to get well, unless unconscious secondary gain from illness or other related psychosocial problems are strongly involved. Children with primarily psychosocial problems may also have a first wish to get well; more commonly, they will wish for something unconnected directly with their disorder, indicating fears of getting well, of having to be independent, of growing up, or other conflicts involved in the unconscious secondary gain or other aspects of the psychosocial disorder.

Preschool children ordinarily wish for things for themselves, though they may remember their parents. Older

Blame may be projected onto medical or nursing staff or onto the spouse.

who have successfully negotiated the initial phasic responses may encounter significant problems, however, in the face of the very real stresses involved, including financial burdens, physical strain or fatigue, discouragement, emotional depletion, and the necessary rearrangement of family patterns of living. At each stage of the child's development, parents also need to mourn again.

One of the central difficulties for parents of children with chronic disorders is the handling of the dependence-independence dimension of child-rearing. Some younger children tend to cling to dependency for security, and their parents may have difficulty in encouraging the child to "move out" physically, socially, and academically within realistic limits. Others may try to push the child toward unrealistic independence, with the child clinging or at times defiant in response. Most parents also have difficulty in talking with the child about his condition, and some may even hide the facts from him. Difficulties in communication may occur between the parents also; a father may be unable to talk about the child's disorder and may give the child's care to the mother while staying away from the situation. Parental overprotectiveness in this regard may limit the child's ability to show concern to the parents.

Parents may differ between themselves in their perceptions of the child's limitations or capacities. This may lead to the situation where one parent pushes and the other protects the child, with consequent serious marital battles. This is especially true if marital disagreements have been present prior to the onset of the child's disorder. The result of such battles in families of children with chronic disorders may be divorce. Some parents search ceaselessly and make unrealistic sacrifices for new and hopefully miraculous treatments; they may also resent the child's failure to be grateful for such strenuous self-sacrifices, developing ambivalent feelings toward him as a result. This tends to contribute strongly to a sense of guilt over imagined disloyalty to the parents in a sick child.

Although such problems occur, a surprisingly large group of parents can adapt successfully to the problems involved in rearing a chronically ill or handicapped child. Such parents can, after the initial phases of response, come to understand and accept the child's limitations; they can permit dependence within limits while helping the child move toward appropriate independence and self-care. They can encourage regular school attendance, and can guide the child in developing compensatory physical and intellectual activities. Such parents see that only the most necessary restrictions are placed upon the child, and that he has opportunities for adequate social and recreational experiences.

Parents who have successfully adapted in this way usually rear children who can successfully cope. In coping with the continuing strain of the situation, however, they tend to use some denial in dealing with an uncertain future and in maintaining hope. Denial and isolation of feelings of helplessness and anxiety may also be employed during an exacerbation of the child's illness or other medical crisis, although as Mattsson[11] has indicated, they may experience later a "rebound phenomenon" involving feelings of depression or irritability. Rationalization is another common defense. Some parents may feel that the child's disability has helped the whole family (which may be true but may help also to ward off too strongly feelings of sadness or resentment). Many parents also use intellectual methods of coping, by reading material or attending lectures dealing with the medical or psychological aspects of their children's disorders. Identification with other parents whose children have similar disabilities can be of positive value to many, though not all, parents, and a number can benefit from being able to help other parents who are beginning to face a similar experience.

Maladaptive patterns of parents also fall along a continuum. The largest group tend to be overanxious, overprotective, and overindulgent, with difficulties in setting limits on the child's demands. These parents usually have been unable to deal successfully with feelings of guilt about failing to "protect" the child from becoming sick or disabled, transmitting the disorder to the child if the disorder is known to have hereditary components, or not wanting the child originally. At times the illness or injury reactivates parental conflicts related to the death of a relative, or the child may have experienced a serious illness at birth or in infancy from which he was not expected to recover. Temperamental differences, the developmental stage at which the disorder appears, and other factors may help to determine the child's response to these parental patterns.

At the other end of the continuum is a much smaller

A child with a chronic condition that limits his activity often has intense feelings of anger or aggressive impulses that cannot be discharged through activity in a healthy fashion.

Anticipatory guidance regarding problems that will face the child or adolescent with a chronic disorder can do much to prevent difficulties. Parents and children should be carefully prepared for necessary medical or surgical procedures or for new steps or phases during the management. As Mattsson[11] has pointed out, such preparation can help to mobilize their psychological defenses and intellectual functions, thus supporting their coping with stress which is anticipated.

In the course of an illness, the physician can assess the progress of parents in handling their feelings about the child's disorder and in arriving at realistic measures of child-rearing. Through pediatric counseling, he can help them to become aware of tendencies toward overprotective, overindulgent, overrestrictive, or neglectful behavior toward their child. The most effective way is to make a tactful observation (gentle confrontation), based on a generalization and followed by a question. "Most parents with a sick child have trouble letting him try things on his own, like taking medications by himself; I've noticed that's a problem for you sometimes—have you thought about it?" Or, "All parents get tired and frustrated at times with a sick child, and may wish they could just walk away. I've noticed you get irritated sometimes. Is it hard to concentrate on what Johnny wants then?"

Overindulgent or overpermissive parents may need to be given "permission" to set limits on their child's behavior or demands; they can be helped to deal with their guilt by being told that limits will help, not harm, their child. This can be offered in the context of a discussion of the child's need to live as normal and happy a life as possible, within his range of capacities, with the added observation that all children need and want some limits, and are not really happy if all their wishes are met.

If the father is distant or uninvolved in the child's rearing, the physician can talk to him alone about the importance of his relationship to his child. He can help the father find activities that he can genuinely share with his child in order to help him or her develop compensatory interests and skills. This is easier for many fathers if the child is a boy, but he can be helped to see that a daughter needs signs from him that he values her as a person and as a woman-to-be. The physician should also try to evaluate by tactful questioning whether the handicapped child's siblings are being given appropriate attention and affection by the parents. If not, he can point out their needs in a sympathetic and noncritical fashion, and can make suggestions as to how their needs can be met. Psychiatric consultation can be helpful for parents who show the maladaptive patterns mentioned earlier. A measure almost universally of value to the entire family is to teach parents to identify and acknowledge an act of devotion or of caring on the part of a child.

Long-Term Management of a Chronic Disorder: Work with the Child

As with the parents, the continuity of the relationship between the child or adolescent and the physician or other health professional is the most basic principle in the approach to long-term management. If the physician leaves town or is away on vacation, it is important that any intercurrent problems be handled by a professional with whom the child and parents are familiar. If the child is in the hospital when such absences occur, it is wise for the primary physician to introduce the child and parents to the physician who will be covering for him. The continuity of the relationship with the primary physician enables him to offer more effective support and counseling along the lines of the development of compensatory interests, the handling of the dependence-independence dimension, and the significant long-range goals and objectives.

A child with a chronic condition that limits his activity often has intense feelings of anger or aggressive impulses that cannot be discharged through activity in a healthy fashion. It is important to let him verbalize these feelings if possible and to permit him to discharge the impulses through channels of play that are appropriate to his condition. For example, a child immobilized in a body cast can be encouraged to make up stories or to draw pictures that will express his feelings or impulses. Children confined to bed at home can, with a plastic sheet covering the bed, use "play dough" (made of flour, salt and water) that permits them to "squeeze hard" and to discharge regressive impulses to soil and mess, in addition to the therapeutic value of acting out their feelings in fantasy around symbolic meanings and activities of the figures, animal or human, they may create.

Allowing the child a chance to ask questions freely... can encourage a sense of confidence and mastery.

In the hospital, a variety of task-oriented activities can be of value. These may be offered under different professional umbrellas: occupational therapy, recreational therapy, and activity therapy. Their methods are somewhat different, but their goals are similar: to help the child achieve pleasure and success, sometimes for the first time since the onset of his illness or handicap, which he can use in later activities; to encourage his participation in group activities; and to prepare him to return to task-oriented endeavors in school or in vocational programs. In children, such activities are best integrated into a play program, with opportunities for appropriate expression of feelings. Educational programs of a flexible nature are also important in hospital settings to help the child retain his orientation toward learning. Some ventilation of feelings may be involved in such programs.[1]

During the course of the chronic condition, parents and child can be helped to focus on small day-to-day steps, thus encouraging hope while not arousing unrealistic expectations. In the hospital, attention can be directed to progress in physical therapy or increase in activity to the point of being discharged; at home, encouragement can be offered toward gradual resumption of individual activities, within realistic limits. Gradual redirection of the child's interests may be of value so that he can compensate for activities denied to him and come to excel in new ones. Allowing the child a chance to ask questions freely and encouraging him to take an active role in taking his own medicine, regulating his diet, etc., can encourage a sense of confidence and mastery. All along, parents and child can be helped to ventilate feelings of frustration, resentment, discouragement, confusion, fear and guilt. It is also useful to encourage groups of children to discuss their concerns about their families. Pediatric discussion groups have been helpful for both parents and children.[7] Psychiatric consultation may be necessary for children and parents who have difficulty in coping, and intensive psychotherapy may be indicated, along with medical measures, for those who are showing signs of the development of maladaptive patterns.

Although a book is no substitute for a relationship with the physician, nurse or health associate, parents can receive important information about the approach to their child's problems from the publication *Caring for Your Disabled Child*, by Spock and Lerrigo,[20] which deals sensitively with the feelings of parents and children while offering sensible advice about a great many things, including such matters as play activities at home, the support offered by parents' groups, and agencies in the community that can offer help in rehabilitation, vocational training, etc.

Comprehensive Care

The writer's experience and that of others would indicate that patient-family satisfaction is much greater when continuity of contact with a primary and coordinating physician is maintained. The Academy of Pediatrics recommends, in its Standards of Child Health Care, that a primary physician be assigned at the outset of the hospitalization to act as a liaiso with the parents, the medical and nursing staffs, and consulting mental health and other professionals. In the writer's opinion, the principles of continuity, communication, collaboration, consultation, and coordination should be maintained on an outpatient as well as an inpatient basis.

Fatal Illness

Many of the problems already mentioned are seen during the course of management of fatal illness and the diffcult task of handling a dying child. The explanation of the diagnosis is not easy, however gently put, and parents show shock, denial, anticipatory mourning, and other aspects of the phasic responses.[4] Helping parents to mourn constructively is the most important task and may prevent other problems. Parents (and hospital staff) are often afraid of the child's response. The young child who is dying expresses mainly his fear of separation from his parents and his wish to avoid pain, as he has as yet no true concept of death. Older children and adolescents often have more understanding about impending death than parents or hospital staff may realize,[10] and even younger children benefit from an opportunity to express their concern abou depressed parents. Staff members often maintain an unconscious "conspiracy of silence," and may stay away from the child to avoid the topic.[18] The recent tendency is to tell children over nine years their diagnosis, with the permission of the parents, and to answer their questions honestly. Assuring them that relief from pain will be available and that they will not be left alone is important. The mutuality of caring is the most valuable resource for the "mourning work" of both parents and children.

Parents should be encouraged[1] to help care for the child, if possible, with much emotional support from the staff. If it is their religious custom, they should be permitted to bring other family members in to mourn with the child. Some parents now wish to take the child home to die, with visits and support from the staff. All parents should be seen within several weeks after the child's death in order to assist mourning, to prevent a "replacement child" and to utilize the resources of the family relationships most fully. In severely traumatized families, the use of a trained family therapist should be considered.

Summary

It is clear that the crux of management of children with chronic disabilities lies in the clinician's understanding of the nature of the impact of the child and his limitations upon the family and of the way in which the family responds to the child's needs. Without considerable awareness of these interpersonal forces as potential resources within the family, no program of habilitation or rehabilitation can fully succeed.

SELF-EVALUATION QUESTIONS

1. Define what is meant by a chronic childhood disability.

2. Discuss the concept of the social field of illness.

3. Within the family equilibrium, specific reactions of parents to chronic illness in children include four phases. Arrange them in order of occurrence.

  a. denial and disbelief
  b. unrealistic fear and frustration
  c. realistic fear
  d. rational inquiry and planning

4. Describe the reactions of the various groups listed below to chronic disability.

  a. young preschool children
  b. late preschool and early school-age children
  c. school-age children
  d. adolescents

5. Few children with chronic illnesses or handicaps are troubled with difficulties in maintaining body image.

  a. true
  b. false

6. Describe the characteristics of parents who adapt successfully to the problems involved in rearing a chronically disabled child.

7. Some parents, for a number of reasons, cannot cope with the burden of a disabled child. Describe the characteristics of this group.

8. Differentiate between the techniques of initial management and long-term management of a chronic disorder.

9. Comprehensive care of a chronic illness or handicap includes____________.

  a. continuity of treatment
  b. communication
  c. collaboration
  d. consultation
  e. coordination
  f. all of the above

10. When managing a fatal illness in a child, the physician____________.

  a. should not discuss the topic of death with either the parents or the child
  b. can assure children they will not be left alone and that relief of pain is available if needed
  c. can help parents mourn constructively
  d. may be afraid of the child's response to knowledge of the fatal illness
  e. all but a

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Handicapism

by Robert Bogdan and Douglas Biklen

Thomas Szasz (1961), Erving Goffman (1963), Thomas Scheff (1966), Robert Scott (1969) and Dorothea and Benjamin Braginsky (1971) taught us to understand "handicap" categories as well as the term "handicap" itself as metaphors. They laid the groundwork for thinking about so-called handicapped people as societally created rather than as a natural or objective condition. These same authors and their associates in the interactionist or labeling school pointed to the importance of the quality and nature of how labelers interact with the labeled as a prerequisite for understanding handicap (see Lemert, 1967; Goffman, 1961; Davis, 1963; Wiseman, 1970). The interface of human service agencies and clients became an area in which social researchers could develop theoretical perspectives on how labels and definitions were applied [illegible] see Gubrium, 1975; Bogdan, [illegible]

While these researchers worked, parallel events occurred in the social action and political arenas. It is not clear who borrowed from whom, but the social construct/labeling school approach to handicap was manifested in a concern for issues of legal and human rights of those labeled handicapped (Kittrie, 1973; Gilhool, 1973). Now a strong "total institution" abolition movement is afoot and various peoples have formed handicap liberation groups. These include Disabled In Action, Mental Patients' Liberation, National Federation of the Blind, The Center On Human Policy, The Mental Health Law Project, and the National Center for Law and the Handicapped (Biklen, 1974; Mental Health Law Project, 1973; National Committee for Citizens in Education, 1976).

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In the field of human services, consumer activism and a new professional consciousness have spawned moral and legal imperatives such as due process, "least restrictive environments," the right to treatment, delabeling, and normalization (Wolfensberger, 1972; Wolfensberger and Zauha, 1973; Abeson, 1974). At present, however, neither the social researchers/theorists nor the social activists have developed an adequate conceptual scheme by which to examine collectively labeling, the moral and legal developments, and the structural and cultural aspects of differential treatment of people defined as handicapped.

Our purpose is to introduce the concept of *handicapism* as a paradigm through which to understand the social experience of those who have previously been known as mentally ill, mentally retarded, deaf, crippled, alcoholic, addict, elderly, deformed, deviant, abnormal, disabled, and handicapped. Handicapism has many parallels to racism and sexism. We define it as a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences.[1] Three terms—*prejudice, stereotype*, and *discrimination*—are inherent in our analysis.[2]

Prejudice is any oversimplified and overgeneralized belief about the characteristics of a group or category of people. Prejudice toward the so-called handicapped is indicated by such indicting assumptions as: they are innately incapable; they are naturally inferior (the mind set is "Thank God, I'm not you"); they have unique personalities, different senses, and different tolerances than the run-of-the-mill citizen; they have more in common with each other than with nonhandicapped persons and, therefore, they like to be with their own kind (see Goffman, 1963; Wright, 1960). These beliefs provide the background assumptions for our action toward people labeled handicapped; they are the essence of handicapism.

Whereas "prejudice" is the general disposition, *stereotype* refers to the specific content of the prejudice directed toward specific groups. The mentally retarded, for example, are believed to be childlike, to enjoy boring routine work, and to be oversexed (Wolfensberger, 1975). The elderly are said to have deteriorated intelligence and are presumed to be unhappy and undersexed. The mentally ill are expected to be erratic in their behavior, are considered dangerous and bizarre, especially during the full moon (see Scheff, 1966; Biklen, 1976). The deaf are considered terrific painters; the blind are supposed to be melancholy (see Scott, 1969, Jernigan, 1975), and supposedly, once an alcoholic always an alcoholic. While sets of stereotypes are often contradictory, they are nevertheless seriously regarded by a number of people and are used to justify particular modes of treatment. Thus the retarded can be treated like children, the elderly ignored, and the mentally ill locked up.

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[1] Authors who have discussed handicapped categories as minority groups include: Dexter, 1964; Wright, 1960; Yuker, 1965; and Gellman, 1959

[2] See Yinger, 1965 and Allport, 1954 for a discussion of the use of these terms in the study of ethnic relations

Although inaccurate, a stereotype is often steadfastly maintained. The maintaining processes are themselves part of handicapism. First peers and culture support the transmission of stereotypes and therefore constantly reinforce them. Second, groups like the handicapped are isolated, have few opportunities for intimate relations to develop between themselves and the so-called normal people, and consequently have little chance of disproving the stereotypes. Last, and perhaps most important, handicapped people are treated in ways that correspond to their stereotypes and are rewarded for living up to others' image of them (see Lemert, 1951). Thus they learn the role of the handicapped and fall victim to the self-fulfilling prophecies (Merton, 1957).

"Prejudice" and "stereotype" point to the cognitive and ideological substance of handicapism. The concept of *discrimination* provides the structural and behavioral aspect. Unfair and unequal treatment of individuals or groups on the basis of prejudice and stereotypes translates into discrimination. Standards of fairness and unfairness vary from society to society and from time to time as the social criteria for equality or discrimination change in accordance with social values. At one time it was considered the natural state of slaves to labor in the fields for the economic benefit of others, and for married women to serve their husbands; the treatment they received was not thought to be unfair. Similarly, handicapped people are generally thought to experience relative equality in this society especially since the advent of various categorical social service programs. They are considered to occupy their rightful place and to receive deserved treatment. For example, few people question the practice of rescinding drivers' licenses, fingerprinting, and taking mug shots of people admitted to state mental institutions despite the fact that there is no evidence that former patients of state mental hospitals are involved in any more accidents or commit more crimes than typical citizens (Scheff, 1966; Ramadas, 1975). It is equally common for public school districts to segregate handicapped children into special classes and even separate "special" schools although there is no empirical evidence to support any benefit, either educational or social, that results from segregated services. These kinds of policies and practices discriminate against people with disabilities. They are part of handicapism.

Two researchers who examined the relationship between physical attractiveness and crime in various media found that physical ugliness and physical differences are often associated with violence and other forms of crime, as shown in the media.

In the remaining pages we will demonstrate how handicapism manifests itself in personal interaction, in the organizational structure of the larger society, and in human service policy and practices. Our purpose is to identify and illustrate handicapism in these spheres, and to demonstrate the usefulness of the concept as a paradigm for social scientists. We have based our discussion largely on current lawsuits, studies reported in the professional literature, and our own research and experiences in the area of social policy and disability.

HANDICAPISM IN INTERPERSONAL RELATIONS

Handicapism arises in the contacts between handicapped and so-called typical people as well as in the private conversations of typical people when the handicapped are not present. In face-to-face contacts, labeled and nonlabeled persons characteristically display anxiety and strain about how each will be perceived by the other (see Davis, 1961; Goffman, 1963; Wright, 1960). "The stigmatized individual may find that he feels unsure of how we normals will identify him and receive him" (Goffman, 1963). And the so-called normals feel that the stigmatized individual is too ready to read unintended meaning into our action. This self-conscious uneasiness results in a number of handicapist practices. For example, nonhandicapped persons avoid contact with "nonnormals." When they are forced into contact they tend to seek the earliest possible conclusion. When there is contact there is also the tendency for the disability (the alleged difference) to take on tremendous significance in the nonhandicapped person's mind: it becomes the master status (Davis, 1961). This often results in the nonhandicapped person either being overly gracious and overly sympathetic ("It must be hell to go through what you go through") or patronizing ("What a lovely belt, did you make that all by yourself?") or in some other ways be insensitive or ignore people with disabilities. One such behavior is to treat them like what Goffman (1960, 1963) calls "nonpersons."

In casual contacts with the handicapped, normals tend to measure them against the stereotype and such contacts reinforce common stereotypes. An example may help to demonstrate this process. Recently a number of typical skiers observed a blind skier coming down the slope. They spoke about him and his "amazing feat." They commented on how "truly remarkable" that he could have the courage and fortitude to do what must be exceptionally difficult for a person with no eyesight. From the tone of their comments it was clear that they did not perceive this person as any *ordinary* blind person. The sighted skiers did not question their stereotypes of the blind as physically inept. Instead, they confirmed the stereotype by classifying this skier as an exception to the rule—as "amazing." If he were not skiing but sitting in the lodge next to the fire, one might expect to hear passers-by whispering to each other something to this effect: "It's a shame that blind people have to miss out on so much fun."

Handicapism is also manifested and perpetuated between normals when not in the presence of disabled people. Stereotypes and prejudice abound in daily conversation: "*Poor* Aunt Jane is going blind." "I'd kill myself if I were as disabled as Luke."

[illegible] casual interpersonal conversation is heavy with handicapist phrases: "Did you hear the one about the *moron* who threw the clock out the window?" "It's like the *blind* leading the *blind*." "You must think I'm *crazy*." "You babbling *idiot*." "What are you, *deaf*?" "Some of the students are real *retards*."

HANDICAPISM AT THE SOCIETAL LEVEL

To understand handicapism at the societal level one must analyze the culture and structure of basic institutions for manifestations of prejudice, stereotypes, and discrimination. Further, one must examine the legally sanctioned and illegal systematic mistreatment of people because of alleged physical, mental, and behavioral differences. And, as in personal interaction, one must study how major societal institutions routinely reinforce and perpetuate prejudice and stereotypes. Since this brief article can only introduce the handicapism paradigm and not exhaustively elaborate it, societal level handicapism is portrayed in only four of the many possible areas: (1) images of the handicapped in the media; (2) physical and literacy barriers to participation; (3) discriminatory laws, rules, and regulations; and (4) exclusion from basic organizations.

Media Images

To what extent does the mass media present prejudicial and stereotypic images of the handicapped? What is the specific content of that imagery? What effect does it have on those who look at it? Impression and data suggest as starting hypotheses that mass media present prejudicial and stereotypic images of the handicapped. After reviewing images of mental illness in the media, Scheff (1966) concludes that mental patients appear stereotypically as bizarre and dangerous. Needleman and Weiner, two researchers who examined the relationship between physical attractiveness and crime in various media, found (1974) that physical ugliness and physical differences are often associated with violence and other forms of crime, as shown in the media. Our own study of horror movies, which are experiencing renewed popularity on the American scene, reveals a clear association of physical and mental handicap with acts of violence and hate. In children's stories there are inevitably hunchbacks, trolls, and other deformed and therefore supposedly frightening people hiding under bridges and in forests to grab pretty children who might be passing by. Disney, for example, frequently promoted handicapist imagery. The wicked witch who gives the beautiful Snow White the poison apple has to change from a beautiful woman to a hunchbacked, wart-nosed old lady to accomplish her terror. Dopey has Down's syndrome-like features and lives with the other childlike dwarfs in the forest. Then there is evil Captain Hook with the patched-eyed pirates of *Peter Pan* fame.

In addition to movies and children's stories, cartoons appear to be important carriers of handicapist images. "Stupid idiot," "moron," "dumb," and "crazy" dot the landscape of comic strip captions. Key offenders include prestigious syndicated strips such as "Beetle Bailey" and "Archie." These comics not only confirm prejudicial and stereotypic attitudes toward people with disabilities, they also reveal that everyday words that refer to specific groups have become general curse words.

HANDICAP
CROSSING
AHEAD

Handicapism takes more direct forms in the media as well. Often newspaper articles link crimes with various disabilities as if the disability was the cause of the crime. For example, in an Associated Press release published across the country a murderer who was scheduled for execution was referred to as "an alcoholic and mentally incompetent psychotic who was mentally retarded." Further, the media promote images of the handicapped as helpless by selectively covering certain events and refusing to cover others. For example, when Kenneth Jernigan, president of the National Federation of the Blind, called a press conference for one of his group's highly political conferences, newspaper and television reporters ignored the political organizational content, for they wanted, instead, to view corporate exhibits of walking aids, lead dogs, and other stereotyping symbols of blindness (Jernigan, 1975). The media promote images of the helpless handicapped by reporting regularly on charity drives that feature posters of crippled children. Telethons promote the same imagery. Their human interest features more often than not proclaim that the handicapped can be helped by charity, thus really reinforcing an image of dependence. One public service advertisement on mental retardation that appeared nationally in newspapers and magazines carried the headline, "He'll be eight years old the rest of his life." The picture was of a child in front of a birthday cake with eight candles. The message was direct and stereotyped; it portrayed the retarded as childlike.

The effect of images of the handicapped in media on audiences has not been studied, perhaps because of the difficulties in isolating such influences. One can hypothesize, however, that it is an important part of handicapism.

Physical and Literacy Barriers

If you were told that because of your race or sex you were not allowed to enter buildings and to use public toilets, sidewalks, and mass transit, you would claim discrimination. People in wheelchairs are denied such access. The degree to which society's constructions and accessways unnecessarily impede participation for a significant segment of our population can be regarded as a primary indicator of handicapism. Recently cities have begun to establish access ordinances, but that did not save the New York City police from an embarrassing handicapist situation. There was a demonstration launched by Disabled In Action in which many of the protestors, who incidentally were in wheelchairs, blocked a road and refused to move. The demonstrators were about to be arrested when the police realized that the jails were not accessible to wheelchairs—a clear violation of state law.

In much the same debilitating fashion that architectural barriers deny access to the physically disabled, written directions (i.e., for tests, applications, forms, and signs) can provide untold obstacles for the person who cannot read and write. Some people leaving state schools for the mentally retarded, for example, report that their inability to read and write creates obvious barriers for their mobility in a society that relies so heavily on written communication. Most bus signs, maps, and street signs require the ability to read. People who cannot learn or simply were never taught to read and write have an extremely difficult time with the many forms such as income tax, employment applications, credit applications, and registration for school (see Dexter, 1964, for a complete discussion). Because it is generally assumed that everyone can and should read, it is terribly embarrassing as well as difficult for people who don't have such abilities to live independently.

While federal legislation has mandated the right to public education for all children with disabilities, The Children's Defense Fund reported that over one million disabled children still remain out of school altogether, ostensibly because of their disability or, more accurately, because of exclusionary policies.

Discriminatory and Exclusionary Laws, Rules, Etc.

For many years it has been common practice for business employers, insurance companies, colleges and universities, and similar organizations to require applicants to identify their disability. The result was discrimination, so much so that the 1973 Vocational Rehabilitation Act mandated no discrimination against disabled workers by agencies that are federally funded. Similarly, some states have passed legislation to end discrimination by all employers and educational institutions (e.g., The 1974 Flynn Act, otherwise known as the Disability Amendments to the Human Rights Law in New York State). Also, the 1973 Vocational Rehabilitation Act established affirmative action requirements for federally funded employers. All of these developments do not suggest that discrimination has ended, merely that widespread discrimination is now acknowledged. Jobs often require physical examinations which automatically exclude disabled people from passing; however, the courts have ruled that all special requirements must reflect the actual nature of the job. Barriers may not be perpetuated simply for the purpose of arbitrarily excluding people with disabilities.

Education, another basic institution in most people's lives, also practices exclusion. Until the 1971 *PARC v. Commonwealth of Pennsylvania* case (Lippman and Goldberg, 1973), the various states freely excluded many handicapped children from public education. While federal legislation has since mandated the right to public education for all children with disabilities (P.L. 94-142, the Education for All Handicapped Children Act), a private research/action group (The Children's Defense Fund, 1974) reported that over one million disabled children still remain out of school altogether, ostensibly because of their disability or, more accurately, because of exclusionary policies.

Still another area rife with exclusionary policies is transportation. Clearly physical barriers create the greatest impediment to disabled people's use of mass transport, but certain modes of transportation have excluded disabled people unless accompanied by an aide. This was the case for several air carriers until a recent challenge by Judy Heumann, a member of the Senate Labor and Welfare Committee and, incidentally, a person whose physical disability requires that she use a wheelchair.

Service Delivery

Ironically, handicapism manifests itself even in the organizations and institutions which have as their official duty the rehabilitation, care, and processing of people who are allegedly handicapped. It seems that most systems that are operating today for the handicapped are based on handicapist principles. Even those that serve clients' specific clinical needs often perpetuate handicapism. First, although the Supreme Court has ruled that separate is inherently unequal, most programs for the handicapped are segregated from the mainstream of society. Not only has society provided state institutions for the retarded, deaf, blind, and emotionally disturbed, governments have financed segregated schools, recreation programs, and sheltered workshops. The large residential institutions and smaller day-service facilities bring together large numbers of labeled people. Alternative integrated placements are usually unavailable. While this separation of the handicapped from the typical population has been recommended by some professionals to facilitate the delivery of services and thus improve the quality of life, research observations contradict this handicapist assertion. Research on the efficacy of separate classes for handicapped children, for example, does not show that children in separate classes achieve any better than children in regular classes (Blatt, 1956; Bennett, 1932; Cain and Levine, 1963; Cassidy and Stanton, 1959; Goldstein et al., 1965; Hottel, 1958; Pertsch, 1936; and Wrightstone et al., 1959). On the other extreme, testimony in recent court cases involving state schools for the mentally retarded [e.g., Willowbrook (N.Y.), Partlow (Ala.), Pennhurst (Penn.), Belchertown, Fernald (Mass.)] gives vivid and definitive evidence of the dramatic regression of skills among people who have been institutionalized.

The culture and structure of service systems for the disabled often work to support handicapism. People are herded, kept waiting, and regimented in barren surroundings designed and maintained to facilitate custodial concerns of cleanliness and efficiency of plant operation (Blatt, 1973; Wolfensberger, 1975; Goffman, 1961; Bogdan et al., 1974; Biklen, 1976; Gubrium, 1975). The handicapped are forced to take endless numbers of examinations. The residential treatment centers including nursing homes, state mental hospitals, and state schools exaggerate handicapist patterns in that residents are often denied personal possessions, have few rights, few opportunities for sexual and other expression, are dressed in ill-fitting clothing, and are often addressed by their diagnosis (i.e., mongoloid, senile, schizoid, low grade).

A cornerstone to the handicapism of professional systems is that services to the disabled people are considered a gift or privilege rather than a right. The American public gives billions of dollars each year to charity, much of which is solicited in the name of helping the handicapped. This system of collecting funds demeans its recipients by supporting the prejudice that the handicapped are inferior people. Moreover, professionals who require charitable contributions to support their programs tend to distort the image of the handicapped in order to play on the public's pity. Thus, the crippled child becomes a poor soul whose disability evokes pity and guilt and the spirit of giving, but also lessens the possibility that disabled people can be regarded as people with personalities, with individual aspirations, and with an interest in being perceived as ordinary people.

The other major funding source for special services is the federal and state governments. But here too the money system promotes handicapism. In order to be eligible for state and federal funds, schools and other human services personnel must label children according to clinical disability categories for which there is reimbursement. They must list the name and diagnosis of the handicap and thereby begin people in their careers of being labeled mentally retarded, learning disabled, autistic, etc. (see Bogdan, 1976; Schrag and Divoky, 1975). In that kind of system the disabled become commodities and agencies become headhunters. In every instance where funds become available for a particular disability group, the number of people so labeled soars geometrically (see Schrag and Divoky). People whose disability might not ordinarily be thought of as a handicap suddenly find themselves labeled; they are pawns in the struggle for agency survival and growth, for they are the essential requisite by which agencies receive government funds. Not too long ago side shows were popular. Deviants were sought out and paraded for a price. While the system we have evolved does not parade its clients, except perhaps during telethons, it does promote labeling and it does thrive on the segregation and exaggeration of the nature and extent of the problem.

NEW STARTING POINTS FOR DISABILITY RESEARCH AND POLICY

Civilizations have always created such categories as "handicapped" and "race" and, along with them, fostered prejudices, stereotypes, and discrimination. Some theorists have suggested that these serve real functions such as allowing us to find targets for our hostility, to find excuses for what goes wrong, to pinpoint people's fear, and to enjoy self-approval in the knowledge that we do not belong to the disapproved of groups (see Erikson, 1966; Barzun, 1965). Barzun suggests that the urge to classify and categorize people is reinforced in modern societies by the belief that scientific theories and systems of facts can account for and explain distinctions between people, differences in temperament and ability, and variation in bodily features and mental habits. By conducting re-

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search and formulating theory on commonsense notions of differences between preconceived categories, and by emphasizing statistically significant differences rather than the range within populations and overlapping of characteristics between categories, social science has done much to reify categories and therefore to entrench prejudice, stereotypes, and discrimination (see Bogdan and Taylor, 1976). Professionals and disability-related fields have followed a research tradition which has hindered the questioning of basic concepts in disability research. A disturbing number of handicapist assumptions have been taken as givens, as starting points for research.

We hope that the handicapism paradigm will enable researchers and practitioners to begin to reassess their assumptions concerning segregated service, differential treatment, the real source of the disability problem, labeling and language patterns, and funding mechanisms tied to labeling. Moreover, the concept of handicapism can facilitate research that will result in policy-related data. While we have not yet explored the full ramifications of handicapism, we have attempted to provide the foundation for conceptualizing the experience of handicaps in a way that will not perpetuate prejudicial notions, but rather will help reveal and erradicate injustice. ■

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Photograph on page 16 by Joseph McNally, in conjunction with a project directed by Burton Blatt and sponsored by the President's Committee on Mental Retardation.

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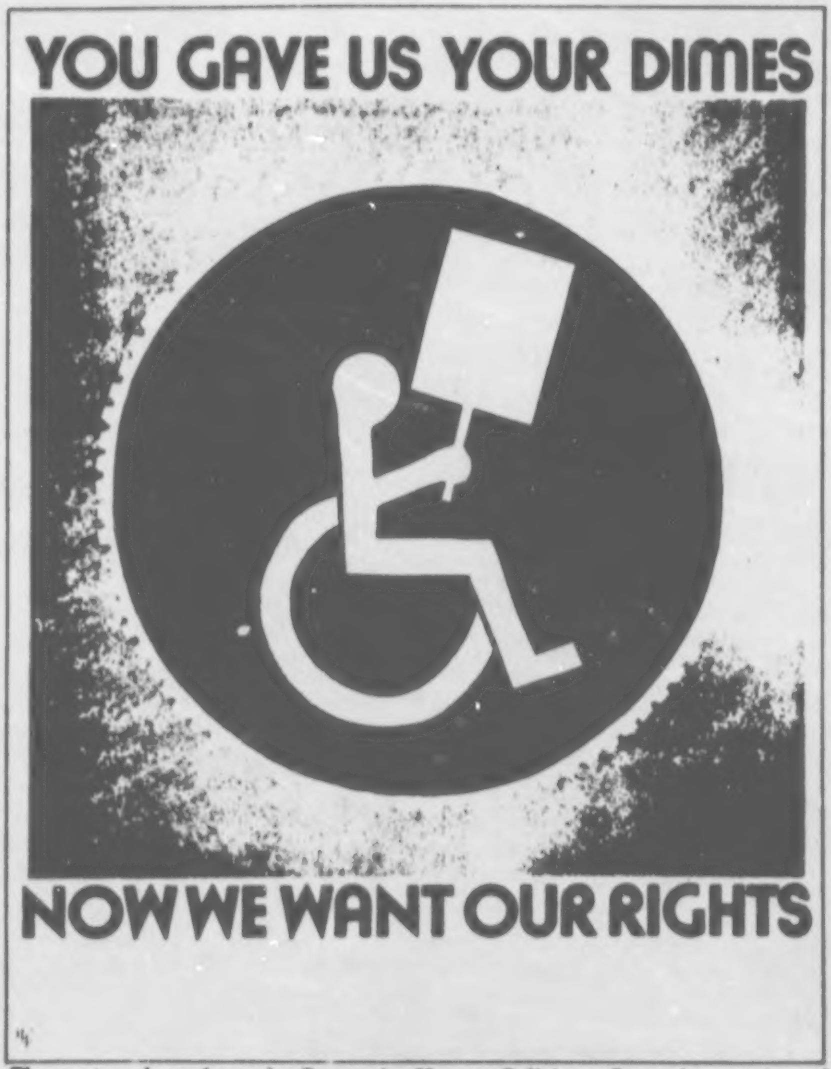
Media Portrayals of Disabled People:
A STUDY IN STEREOTYPES

By Douglas Biklen and Robert Bogdan


YOU GAVE US YOUR DIMES
NOW WE WANT OUR RIGHTS

The poster above from the Center for Human Policies reflects the activism of the disability rights movement.

"Handicapism" refers to the stereotyping, prejudice and discrimination practiced by society against disabled people.[1] The term provides a perspective by which we may analyze experiences, policies and practices related to disabilities.

Handicapist barriers have prevented the integration of disabled people into the mainstream of our society. This has made it easy to ignore the extent to which disability affects our population. Far from being a condition that affects only a few people, disability affects significant numbers of our population. The American Coalition of Citizens with Disabilities estimates that disabilities affect 36 million people—one out of every six people in the U.S.

As this sizeable and increasingly activist group of disabled people voices its concerns (see page 16), we become more aware of the extent to which handicapism pervades our society. Handicapism is prevalent in education, employment, literature, the mass media, architectural and trans-

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[1] The word "handicap" comes from the practice of beggars who held "cap in hand" to solicit charity—and the word reflects the dependent position in which society places disabled people.

The authors wish to express their indebtedness for the pioneering work of Bruce Dearing, Barbara Baskin, Abby Campbell Hunt and Madeleine Cohen Oakley in the area of disability stereotypes in literature and film. They also appreciate the insights on disabilities in folk-tales shared by Patricia Crook.

portation design and in a multitude of other areas. Handicapism *affects* us *all*—both disabled and non-disabled people—just as we are *all* affected by racism, sexism, ageism and other negative, harmful attitudes.

One of the manifestations of handicapism—again as with racism, sexism, etc.—has been a profusion of negative stereotypes that serve to reinforce society's oppression of a minority group. As with stereotypes about Third World people and women, some stereotypes about people with disabilities draw upon—but distort—reality. While disabled people *do* experience some real limitations—decreased ability to hear, see or walk, for example—*most* of the limitations associated with being disabled derive from society's response to disability. (As one activist has said, "Our bodies make us disabled, but society makes us handicapped.") Society's negative stereotypes also draw upon myth, reflecting "truths" that upon close examination turn out to be false. Businesses, for example, frequently state that hiring a disabled worker will be costly in terms of insurance, special privileges, time missed for illness, etc., whereas studies show that none of these "facts" is true.

An interesting aspect of stereotypes about disabled people is that they often embrace two diametrically opposed concepts. In the same way that women have sometimes been viewed as either "saints" or "whores," perceptions of disabled people often reflect "two-sides-of-a-coin" extremes. (People with disabilities are, for example, seen as asexual and, on the other hand, as insatiable "sex degenerates"; as helpless victims of violence and, at the same time, as evil and frightening villains.) In addition, as will be pointed out, handicapist stereotypes are often interrelated and reinforce each other.

We believe with the Council on Interracial Books for Children that an effective way to begin counteracting handicapist stereotypes is to alert readers, especially young readers, to their presence. As a step toward this goal we have informally surveyed a range of classic literature as well as popular contemporary media. We have concluded that although a few books and films treat disabilities sensitively and accurately, most do not.

We observed, too, that even the most sensitive materials overplay individual solutions to disability prob-

Disabled—Yes; Handicapped—No: The Language of Disability

Society's misconceptions about people with disabilities are reinforced by negative, handicapist terms—terms like "cripple," "spastic," "idiot." Continued use of these words contributes to the negative self-images of disabled people and perpetuates handicapist attitudes and practices.

One goal of the disability rights movement is the elimination of handicapist language—in speech, in media, in classrooms, in library card catalogs. The CIBC urges parents, librarians and teachers to be alert to handicapist terms and, when these words do come up, to ask that people think about their offensive implications.

Try to avoid all terms that dehumanize or objectify disabled persons, all terms that characterize disabled persons as dependent or pitiable, all terms that perpetuate the myth that disabled persons are incapable of participating in the life of a community.

There is considerable controversy about some terms. The word "handicap" is rejected by many disability rights activists because of its historic associations with "begging" and society's negative stereotypes. However, it is still the preferred term of the federal government and is the terminology used in the new legislation to protect disabled people against discrimination. The term "exceptional" has been favored for a number of years by some advocacy groups -for example, the Council for Exceptional Children in Reston, Virginia, and *Exceptional Parent*, a journal published in Massachusetts for parents of disabled children. Many disability activists consider this a euphemism. Massachusetts recently passed a law—Chapter 766—that prohibits labeling of any kind. Children with disabilities in Massachusetts are henceforth to be identified only as "children with special needs." The Massachusetts law is considered to be progressive, but there is some criticism that it gives legitimacy to a phrase that emphasizes a person's "neediness."

In deciding on terminology, *Bulletin* editors gave serious consideration to "physicalism," another term advanced by disability activists. Physicalism may be defined as discrimination based on physical appearance and was, therefore, considered too broad a referent for the kinds of disabilities discussed in this *Bulletin*. Future *Bulletin* articles will explore the broader topic.

We have selected the word "disability" as a positive reference to physical or developmental conditions, but we have used "handicapism" because of its negative connotations to describe society's oppression of disabled people.

Below are examples of terminology which, in the light of the new awareness, are considered to be offensive. Preferred substitutes are listed to the right. Some of these terms may appear awkward when first used, but groups using them find that they become readily acceptable after a short while.

OFFENSIVE	PREFERRED
handicap, handicapped person	disability, disabled person
deaf and dumb, deaf-mute, the deaf	deaf, hearing disability, hearing impairment
mongoloid	Down's syndrome
cripple, crippled	orthopedic disability, mobility impaired, disabled person
the blind	blind person, sight disability, visually impaired
retard, retardate, idiot, imbecile, feeble-minded	retarded, mental impairment, mentally disabled
crazy, maniac, insane, mentally ill	emotional disability, emotional impairment, developmentally disabled

RELATED TERMS TO AVOID: The Minnesota 1976 Governors Conference on Handicapped Individuals proposed that the following entries be deleted from library catalogs: Abnormal children; Abnormalities, Human; Atypical children; Children, Backward; Children, Retarded; Children, Feeble-Minded.

lems without referring at all to societal factors that can cause disability, or to societal discrimination against disabled people (see page 20).

Drawing on the images of disabled people revealed by our survey we have compiled the following tentative list of handicapist stereotypes. The list is a first step, intended mainly to alert readers and stimulate thought. We ask you to join us in further illuminating handicapist stereotypes and in developing strategies to counteract handicapism.

In Johanna Spyri's Heidi, *published in 1881, young Heidi is a hired companion to "the rich little cripple" Clara, who fits the "poor, pathetic" stereotype. Clara's disability vanishes at story's end due to a cure composed of Heidi's affection, fresh mountain air and goat's milk. (The story contains other questionable messages. In one passage, Heidi tells young Peter that unless he learns how to read, he'll be sent to the Hottentots—and this threat terrifies him.)*

Handicapist Stereotypes

1. **The disabled person as pitiable and pathetic.** This image is often projected in newspapers and in charity drive solicitations for "the needy" or "handicapped." Remember the old "March of Dimes" posters? Though the posters have been changed in response to protests, the concept is still alive and well in the yearly telethons held to raise money for people with cerebral palsy and muscular dystrophy. (At a 1977 demonstration protesting the annual United Cerebral Palsy Telethon, Disabled in Action, a disability rights organization, stated: "Fund-raising telethons are demeaning and exploitive 'shows' which celebrate and encourage pity.")

In literature the pitiable and pathetic stereotype is reflected in the characterizations of Philip Carey in *Of Human Bondage* and Laura Wingfield in "The Glass Menagerie." This stereotype is often used by authors as a device for revealing another character's goodness and sensitivity. In such instances, the disabled persons seem to have been included primarily so that a main character can be seen showing love, kindness and pity toward them. "Pitiable and pathetic" characters are often portrayed as having hearts of gold, which serves to elicit even greater feelings of pity (rather than genuine compassion) from audiences or readers. Tiny Tim in *A Christmas Carol* is an example, as is Porgy in the Gershwin opera *Porgy and Bess.* This patronizing stereotype springs in part from the feelings of superiority that non-disabled people harbor towards people with disabilities.

2. **The disabled person as object of violence.** In reality, disabled people are often victims of violence. However, the absence in literature and other media of a full range of roles for disabled people renders this type of portrayal a stereotype that strongly reinforces society's view that people with disabilities are totally helpless and dependent. The films "Woman in a Cage" and "What Ever Happened to Baby Jane?" are examples. In the former, Olivia DeHavilland, in a wheelchair, is trapped in an elevator by a band of youthful thieves while they ransack her apartment. In the latter, Joan Crawford (also in a wheelchair) is wholly at the mercy of her diabolical and murderous sister, Bette

Davis. Another example is "Wait Until Dark," in which a blind Audrey Hepburn ultimately outwits a bunch of thugs but only after they have thoroughly terrorized her in their search for a drug cache in her house. TV crime shows often sensationalize violent assaults against people with disabilities.

3. The disabled person as sinister and/or evil. The classic example of this common stereotype is Shakespeare's *Richard III*. Exploiting people's negative perceptions of physical disability, Shakespeare distorted the appearance of the king (who in real life was not disabled) to accentuate the evil dimension of his personality:

> I, that am curtail'd of this fair proportion,
> Cheated of feature by dissembling nature,
> Deform'd, unfinisht, sent before my time
> Into this breathing world, scarce half made up,
> And that so lamely and unfashionable
> That dogs bark at me as I halt by them
> Why, I, in this weak piping time of peace,
> Have no delight to pass away the time
> Unless to spy my shadow in the sun,
> And descant on mine own deformity:
> And therefore, since I cannot prove a lover,
> To entertain these fair well-spoken days,
> I am determined to prove a villain,
> And hate the idle pleasures of these days. (Act I, Sc.i)

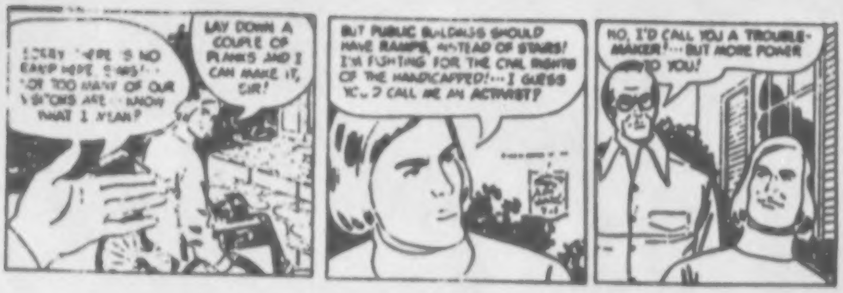
Captain Ahab in Herman Melville's *Moby Dick* becomes so undone by the white whale's destruction of one of his legs that he sacrifices himself and most of his crew in obsessive pursuit of revenge. Melville uses Ahab's disability to build a sinister and foreboding atmosphere as, for example, when narrator Ishmael hears Ahab's false leg tapping back and forth across the deck in the middle of the night.

In fairy tales, there is the malicious *Rumpelstiltskin* and the mean witch (who "leans upon a crutch") in *Hansel and Gretel*. Classic children's literature has exploited this stereotype to the hilt. Take Stevenson's *Treasure Island*. In evoking the terror and suspense that mark this book's opening pages, the key elements are the disabled characters Black Dog and Pew. The former is introduced as a "tallow-faced man, wanting two fingers." This minor disability sets a tone that is built up when the second man is described as that "hunched and eyeless creature," and it is the latter who hands Billy Bones the dread black spot. In addition, when Long John Silver is introduced as a good guy, there is only a casual mention of the fact that he has a wooden leg. Later, when his treachery is revealed, the references to his "timber" leg become ominous and foreboding.

The stereotype of the disabled person as pitiable objects of charity is often exploited by fund raisers. Although the old March of Dimes posters no longer appear, the poster children do (photo: New York Post, *August 31, 1977).*

Examples in modern media are the maniacal and fascistic Dr. Strangelove in the movie of the same name, who has multiple disabilities; the villains in the movies "Dirty Harry," "The Sting" and "Burn, Witch, Burn"—all of whom limp; and the profusion of disabled villains in the James Bond films.

4. The disabled person as "atmosphere." Blind musicians, newsdealers and the "blind man with a cup" are frequently thrown in for seasoning in movies and TV stories, a practice which dilutes the humanity of disabled people by reducing them to the status of colorful or curious objects. They become like Sherlock Holmes' hat and pipe or Detective Columbo's rumpled raincoat. Related to this stereotype is the depiction of disabled people as exotica. People who are displayed in so-called "freak shows" are victims of this stereotype


SORRY THERE IS NO RAMP HERE, SIR!... NOT TOO MANY OF OUR VISITORS ARE... KNOW WHAT I MEAN?
LAY DOWN A COUPLE OF PLANKS AND I CAN MAKE IT, SIR!
BUT PUBLIC BUILDINGS SHOULD HAVE RAMPS, INSTEAD OF STAIRS! I'M FIGHTING FOR THE CIVIL RIGHTS OF THE HANDICAPPED!... I GUESS YOU'D CALL ME AN ACTIVIST?
NO, I'D CALL YOU A TROUBLE-MAKER!... BUT MORE POWER TO YOU!

Disability rights were recently discussed in the Mary Worth comic strip, though sometimes with mixed messages as shown above. Below, an advertisement for Hathaway shirts plays on the stereotype of disabled men as "sexy."

(General Tom Thumb, a dwarf in P.T. Barnum's sideshows, is a famous example). These shows are, in a sense, disability pornography in that they encourage prurient fascination with disabilities.

5. **The disabled person as "Super Crip."** This stereotype is somewhat akin to the depiction of Third World characters as having "super" qualities to make them deserving of acceptance and respect by white people, except that with disability, the person is often assigned what amounts to a magical ability. "Longstreet" and "Ironsides," TV's super private eyes, are striking examples. Longstreet, who is blind, has developed superhuman hearing to offset his inability to see. Ironsides, though paralyzed, has extraordinary mental powers as well as unusual calm in the presence of adversity. His name, colloquial for wheelchair, echoes the naming of characters according to their disabilities found in many children's books (see article, page 10). A positive feature of "Ironsides" is that the show has helped educate viewers about architectural access issues and has underscored the importance of certain aids to some physically disabled people. Unfortunately, the various ramps and other special aids available in Ironsides' fictional environment are not provided for disabled people in real life. Real-life expressions of this stereotype appear frequently on the pages of the *National Enquirer, Midnight, Readers' Digest* and other publications which regularly feature the extraordinary achievements of disabled persons who "overcome"—thus becoming a credit to their "race."

6. **The disabled person as laughable.** The nearsighted Mr. Magoo is the quintessential fool, epitomizing society's perceptions of certain conditions of being—in this case, physical disability—as humorous. Blissfully unaware of his nearsightedness, Magoo bumbles through life wreaking much havoc and unmindful of numerous dangers to himself. Although he survives everything, we—the aware audience—know that his survival is due only to chance and not to ingenuity on his part. The old Dean Martin/Jerry Lewis films (still being rerun on TV) often featured Lewis mimicking various disabilities and thereby soliciting many a laugh. And a recent skit on the Richard Pryor show portrayed with extraordinary insensitivity the condition of people with disabilities. Pryor apparently intended to satirize religious "quacks" who exploit people, but in the process disabled people got put down too. People who have suffered hearing loss are frequently made the butt of jokes in comedy routines when they misinterpret what is said to them.

Some stories portray a disabled person as the brunt of other people's chicanery. In the Russian folk-tale *The Little Humpbacked Horse*, Ivan the Dullard is helped out of numerous jams by the "Super Crip" horse—who has magic powers. Yet an aspect of this story, as with many similar tales, is that the one presumed to be foolish inadvertently makes fools of the so-called "normal" characters. This recurring theme is undoubtedly a kind of stereotype but one that results in poetic justice.

7. **The disabled person as his/her own worst—and only—enemy.** The popular media often portray disabled people as self-pitiers who could "make it" in society if only they would stop being "bitter" about their "fate," think positively and rise to The Challenge. The legitimate anger which disabled people may feel about society's abuse is misrepresented as unfounded bitterness that has its roots in the person's character. Hence, this stereotype helps "normal" people to avoid confronting the anger's true causes—which implicate the attitudes and practices of "normals" and of "normal" society. Just as victims of racist or sexist oppression are blamed for adversities they encounter, so does this stereotype place blame on disabled people for their difficulties. TV medical shows like "Marcus Welby, M.D." are some of the worst offenders here. These shows generally ignore the institutional barriers society places in the way of disabled people, as well as the pervasive and devastating discrimination they experience. As will be pointed out in the next article, children's authors seem to be especially fond of this stereotype, perhaps because they regard it as effective for promoting self-help and determination in young readers. But given the realities, a degree of self-pity on the part of disabled people may be quite functional and appropriate.

8. **The disabled person as burden.** This stereotype is linked to the concept that all people with disabilities are helpless and need to be taken care of by "normal" people. While it is true that disabled people have a range of special needs—from mild to severe—the perception that they are burdens is engendered by the difficulties our society imposes on meeting their needs. Generally speaking, a burden is something one wishes to be rid of; hence, the constant recurrence of the "burden" image in media objectifies and dehumanizes. At the same time, it can falsely enhance the image of the person who bears the "burden" at the expense of the disabled person. It's important to

recognize that people with disabilities are, first and foremost, human beings who are capable of much independence and of interacting with others in mutually rewarding ways. Lenny, the mentally retarded character in *Of Mice and Men*, is an interesting case in point. While most people view Lenny as being utterly helpless and dependent on hero George, actually Lenny's physical strength provides the economic basis of George's livelihood. In addition to feeling affection and caring for Lenny, George is dependent on *him*.

9. **The disabled person as nonsexual.** Disabled people are almost always portrayed as totally incapable of sexual activity. Remember the song "Ruby, Don't Take Your Love to Town" that was popular during the Vietnam war years? A veteran begs his lover not to let a war injury that has incapacitated him sexually come between them. A more common manifestation of this stereotype, however, is omission of the sexual dimension from characterizations of people who are disabled. In fact, they are rarely shown in a loving relationship of any kind. The previously cited Detective Ironsides is portrayed as having *had* a love life once upon a time before he was shot in the spine, and, thus, put out of commission. His "old flames" turn up occasionally to join him in soulful reminiscences about their lost love, but nothing's happening in the here and now. (Again, although some disabilities may limit an individual's sexual activity, the assumption that disabled people are non-sexual beings is false and unreal.) Interestingly, shows are beginning to appear on TV that in some ways counter this particular stereotype. "Other Side of the Mountain," the story of Jill Kinmont, is a particularly honest film.

The flip side of this stereotype is the portrayal of disabled persons as sex-starved or sexually degenerate (comic books are particular offenders here). Another curious reversal is that *men* with certain mild disabilities—especially ones sustained in war—are often viewed as exceptionally brave and/or sexy. This image has been effectively exploited in the "classic" ads for Hathaway shirts featuring a man with an eye patch (this campaign, first used in the 1950's, has recently been revived). Lord Nelson and Moshe Dayan are real-life examples. In a macho society, women similarly disabled are not seen in such a glamorous light.

10. **The disabled person as incapable of fully participating in everyday life.** This stereotype is mainly one of omission in that disabled people are rarely shown as integral and productive members of society—as part of the work force, as functioning members of families, as students or teachers, etc. The absence of such portrayals feeds the concept that disabled people are inferior human beings who should be segregated (a concept that fortunately seems to be on the way out). Movies like "Charly" and "Larry," about mentally retarded people, reinforce this concept. Charly is presumed to be incapable of doing anything except sitting on a park swing. Larry is reintegrated into society *only* when it's discovered that he isn't retarded—the implication being that retarded people are hopeless dependents who require lifelong institutionalization. Regular inclusion of disabled people as participants in society would lend emphasis to the extremely wide range of things they *can* do, rather than to what they cannot do. ☐

About the Authors

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Avoiding Handicapist Stereotypes:

GUIDELINES FOR WRITERS, EDITORS AND BOOK REVIEWERS

The guidelines below were prepared by the Center on Human Policy, the Center for Independent Living in Berkeley, Disabled in Action of Metropolitan New York and the Council on Interracial Books for Children. They are offered as suggestions to assist authors, editors, reviewers and readers in counteracting the common stereotypes about disabled people that are outlined in the article, "Media Portrayals of Disabled People: A Study in Stereotypes," beginning on page 4.

- Shun one-dimensional characterizations of disabled persons. Portray people with disabilities as having individual and complex personalities and capable of a full range of emotions.
- Avoid depicting disabled persons only in the role of receiving; show disabled people *inter*acting as equals and giving as well as receiving. Too often the person with a disability is presented solely as the recipient of pity.
- Avoid presenting physical characteristics of any kind as determining factors of personality. Be especially cautious about implying a correlation between disability and evil.
- Refrain from depicting persons with disabilities as objects of curiosity. It is entirely appropriate to show disabled people as members of an average population or cast of characters. Most disabled people are able to participate in all facets of life and should be depicted in a wide variety of situations.
- A person's disability should not be ridiculed or made the butt of a joke. (Blind people do not mistake fire hydrants for people or bump into every object in their path, despite the myth-making of Mr. Magoo.)
- Avoid the sensational in depicting disabled people. Be wary of the stereotype of disabled persons as either the victims or perpetrators of violence.
- Refrain from endowing disabled characters with superhuman attributes. To do so is to imply that a disabled person must overcompensate and become superhuman to win acceptance.
- Avoid a Pollyanna-ish plot that implies a disabled person need only have "the will" and the "right attitude" to succeed. Young readers need insights into the societal barriers that keep disabled people from living full lives—systematic discrimination in employment, education and housing; inaccessible transportation and buildings; and exorbitant expense for necessities.
- Avoid showing disabled people as non-sexual. Show disabled people in loving relationships and expressing the same sexual needs and desires as non-disabled people.

Chapter 1:

What Is Mainstreaming?

1

Mainstreaming calls for helping handicapped children to perform as much as possible like other children their age.

From: Mainstreaming Pre-schoolers
by the Head State Bureau

4

What Does Mainstreaming Mean?

"Mainstreaming" means helping people with handicaps live, learn, and work in typical settings where they will have the greatest opportunity to become as independent as possible. In Head Start programs, mainstreaming is defined as the integration of handicapped children and non-handicapped children in the same classroom. It gives handicapped children the chance to join in the "mainstream of life" by including them in a regular preschool experience, and gives non-handicapped children the opportunity to learn and grow by experiencing the strengths and weaknesses of their handicapped friends.

However, mainstreaming involves more than simply enrolling handicapped children in a program with non-handicapped children. It calls for helping handicapped children to perform as much as possible like other children their age. Definite steps must be taken to ensure that handicapped children participate actively and fully in classroom activities. As a Head Start teacher, it is your role to take these steps.

Mainstreaming is not new to Head Start. Since its beginning, Head Start programs have included handicapped children in classrooms with non-handicapped children. The Economic Opportunity Amendments of 1972 (Public Law 92-424) required that ten percent of the Head Start enrollment in the nation be handicapped children. Two years later, the Head Start, Economic Opportunity, and Community Partnership Act of 1974 required that, by fiscal year 1976, not less than ten percent of the total number of enrollment opportunities in Head Start programs in each state be available to handicapped children. And most recently, Public Law 94-142, the Education for All Handicapped Children Act, has mandated that the public schools provide "free, appropriate education" in the "least restrictive setting" for handicapped children from 3 to 21 years of age. Thus, mainstreaming has become an important and well-accepted approach in the education of young handicapped children.

It is the function of Head Start programs to:

> **serve handicapped children in an integrated setting or mainstream environment with other children; provide for the special needs of the handicapped child; and work closely with other agencies and organizations serving handicapped children in order to identify handicapped children, and provide the full range of services necessary to meet the child's developmental needs.**
>
> (Head Start Transmittal Notice 75.11 — 9/11/75.)

Research on children has shown over and over that the early years of life are critical for learning and growth. It is during this time that children's cognitive, communicative, social, and emotional development can be most influenced. If special needs are recognized and met during these years, handicapped children will have a much better chance of becoming competent and independent adults. Handicapped youngsters who are given the opportunity to play with other children in the Head Start classroom learn more about themselves and how to cope with the give-and-take of everyday life. This is one of the first steps toward developing independence. By participating in regular preschool settings that are able to provide for special needs, with teachers who know how to adapt teaching techniques and activities, children with special needs will truly have a "head start" in achieving their fullest potential.

Benefits of Mainstreaming

There are many benefits to mainstreaming — benefits that affect both handicapped and non-handicapped children, as well as their parents and teachers.

Mainstreaming Helps Handicapped Children

Participating in a mainstream classroom as a welcome member of the class teaches children with special needs self-reliance and helps them master new skills. They are given a chance to learn, play, communicate, and socialize as do other children their age. For some, it may be the first time in their lives that they are expected to do for themselves the things they are capable of doing. Working and playing with other children encourages handicapped children to strive for greater achievements. Working toward greater achievements helps them develop a healthy and positive self-concept.

Mainstreaming can be an especially valuable method for discovering undiagnosed handicaps. Some handicaps don't become evident until after a child enters elementary school, and by then much important learning time has been lost. A preschool teacher is able to observe and compare many children of the same age, which makes it easier to spot problems that may signal a handicap. Preschool may therefore be the first chance some children get to receive the services they need.

Mainstreaming Helps Non-handicapped Children

Mainstreaming can help non-handicapped children, too. They learn to accept and be comfortable with individual differences among people. Studies have shown that children's attitudes toward handicapped children can become more positive when they have the opportunity to play together regularly. They learn that handicapped children, just like themselves, can do some things better than others. In a mainstream classroom, they have the opportunity to make friends with many different individuals.

Mainstreaming Helps Parents

Mainstreaming is also good for the parents of children with special needs. With you (the teacher), the other members of the staff, and specialists sharing the responsibility for teaching a child, the parents come to feel less isolated. They can learn new ways to help their own child. As they watch their child progress and play with non-handicapped children, parents are helped to think about their child more realistically. They will see that some of the behavior they are concerned about is probably typical of all young children, not just children with handicaps. In these ways, parents come to feel better about their children and themselves.

Mainstreaming Helps Teachers

Mainstreaming also has advantages for you. You have the chance to make a significant impact on a handicapped child. The techniques you develop for working with a child with special needs are just as useful with non-handicapped children who have minor weaknesses in the same areas. In fact, many of the most effective teaching techniques known were first developed for handicapped children. Finally, working with handicapped children is a chance to broaden both your teaching and personal experience.

6

How Is Mainstreaming Carried Out?

Mainstreaming can be carried out in a variety of ways. How you decide to mainstream a particular handicapped child will depend upon the child's strengths, weaknesses, and needs, and will also depend upon the parents, the staff and resources within your program, and the resources within your community. As you know, every child is an individual with different needs and abilities. This is just as true for handicapped children: they display a broad range of behavior and abilities.

Some handicapped children may thrive in a full-day program with nonhandicapped children. Others will do best in a mainstream environment for only part of the time, attending special classes or staying at home for the rest of the day. For still others, mainstreaming may not be the most helpful approach. The principle to follow is that handicapped children should be placed in the "least restrictive environment." This means that the preschool experiences of handicapped children should be as close as possible to those of nonhandicapped children, while still meeting the special needs created by their handicaps. The "least restrictive environment" should be *individually* determined for a *particular* child at a *particular* time, and reassessed on an ongoing basis.

Mainstreaming involves the efforts of many people working as a team — teachers, the child's parents, Head Start staff (in health, education, handicap, parent involvement, and social services), other specialists providing consultant services on a full- or part-time basis, agencies serving handicapped children, and the public schools in the community. The identification, development, and coordination of this team effort is both a challenge and a critical requirement in meeting the needs of a handicapped child.

As you and your program staff get to know each child, and as you work with the child's parents and specialists in your community's agencies and public schools, you will be able to decide what is best for each child. This book describes *how* mainstreaming of hearing impaired children can be carried out by the parent/Head Start/specialist team in order to provide the best program for both handicapped and nonhandicapped children.

This book discusses hearing impairment and how it affects a child's development. Categories are used to describe different degrees of hearing impairment, as well as different functioning abilities. The book focuses on oral communication as the main problem for a hearing impaired child, and discusses how problems with communication affect other areas of development (see Chapter 3). It also considers why a hearing impairment presents more serious communication problems for some children than for others, and how the seriousness of a child's problems relates to mainstreaming decisions. (See Chapter 4, page 38, for a discussion of what to consider in mainstreaming a hearing impaired child.)

Specific teaching techniques for use with hearing impaired children are suggested in Chapter 4 for teachers without special training. The techniques and suggestions given are most appropriate for a child who functions as hard of hearing. As defined in Chapter 2 (page 12), this child can use his or her hearing for the ordinary purposes of life and may or may not use a hearing aid. This book cannot help you teach a child who is functionally deaf. This child is defined in Chapter 2 (page 12) as unable to use his or her hearing with or without a hearing aid for the ordinary purposes of life. Regardless of the child's degree of hearing loss, he or she *must* have already developed some useful communication skills in listening, understanding, and talking in order to benefit from a mainstream classroom.

The potential to improve on these skills is there. The mainstream classroom provides daily opportunity to encourage the growth of these skills.

Suggestions are also given for how to refer a child with more serious hearing and communication problems to the proper specialists and/or to a more appropriate educational setting.

What Is Your Role in Mainstreaming?

This book approaches mainstreaming from the standpoint of child development. It emphasizes the importance of seeing handicapped children first and foremost as children, with the same needs all children have for love, acceptance, exploration, and a sense of competence. By understanding how all children develop and learn you can better understand the effects of a particular handicapping condition. For example, knowing the importance of hearing for language learning will help you understand the effects of hearing impairment on a child's development of communication skills. And knowing how children normally develop the skills of listening, understanding, and talking will help you to know what a hearing impaired child's present developmental needs are. You can then use this knowledge to plan appropriate activities for building on a child's strengths and working on his or her weaknesses.

The teaching techniques and suggestions provided in this book are designed to help develop skills in particular areas of development — primarily listening, understanding, and talking, and additionally, cognitive, social, and emotional skills — and can be used with any child or group of children in your classroom, whether they are handicapped or nonhandicapped.

As a teacher, your role in mainstreaming includes:

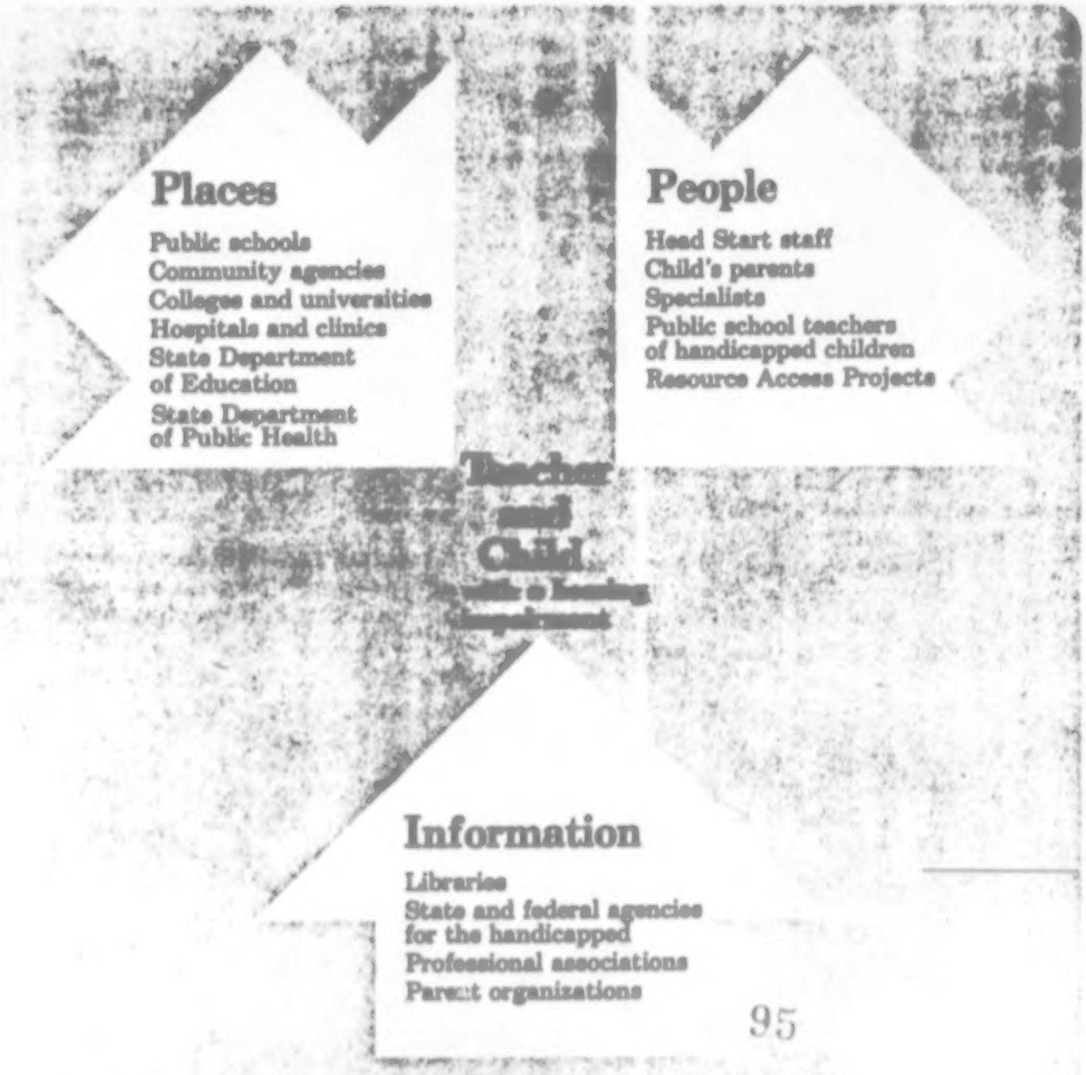
- developing and putting into effect an individualized program that meets the needs of each child in the classroom, including the special needs of a child with a handicapping condition
- working together with the parents of a handicapped child so that learning situations that occur in your classroom are reinforced by the parents at home
- finding out, through your handicap coordinator or social services coordinator, what special services a handicapped child is receiving and how you can get a specialist to help you in your classroom teaching
- arranging referrals through your handicap coordinator or social services coordinator for diagnostic evaluation, if you feel a child has a

problem that has not been clearly identified.

In carrying out this role, there are many resources that can be tapped to assist you. Later in the book they will be described in more detail, but they are summarized on the following chart.

Where to Go for Help

There are many resources you can tap for help with a handicapped child. Take advantage of these resources by actively seeking them out. For detailed information on Head Start and other resources in your area, see Chapter 6. For detailed information on national professional and parent associations and other organizations, and a list of helpful materials, see Chapter 7.



Places

- Public schools
- Community agencies
- Colleges and universities
- Hospitals and clinics
- State Department of Education
- State Department of Public Health

People

- Head Start staff
- Child's parents
- Specialists
- Public school teachers of handicapped children
- Resource Access Projects

Teacher and Child with a hearing impairment

Information

- Libraries
- State and federal agencies for the handicapped
- Professional associations
- Parent organizations

About Disabilities *

There are some who say that the disabled child is simply like any other child. There's almost no difference, they argue. They'd rather not notice. Others point only to difference, suggesting that disabled children might be better off with their own kind. It's not the child's fault, they add, it's just too bad. They notice too much.

Among the various special needs of disabled children, none may be more pervasive, more special, than the need to be understood. Certainly none is more beyond the disabled child's individual ability to control. For, in the face of those who may not see, hear, walk, speak or understand as well as other, we pile obstacles of mystery, misconception and misunderstanding. The irony is indeed cruel.

Unfortunately, most children do not have an oppurtunity to learn even basic information about disabilities. Instead they learn by omission. And what they learn are the great myths. When we interviewed hundreds of school children about disability issues, we found out that non-disabled children tend to think that their disabled peers are sad most of the time. When asked what occupations disabled people will have, children told us about "blind newspaper stand operator," "deaf printers," and other stereotypes. (It was a refreshing surprise to find that one child drew a colorful picture of a person in a wheelchair located on a scaffolding near the top of a high-rise building, washing windows.) Children also told us that they think disabled children are actually "sick". These are some of the myths that we want to help overcome.

We present some brief information about disabilities to help deflate the major myths about disabilities, not to create or confirm them. Labeling of name-calling. It almost always leads to stereotyping and/or over-simplification; it is inhibiting and damaging not only to the "tagged" person, but also to the "tagger" who, presumably non-disabled, is oblivious to the disabled person's context and reality. Labeling encourages generalizationa and fosters the lumping or categorizing of people within a context of deficiency, rather than capability. People with the same disability are almost always very different from each other, in the same way that any person is different from another person. But labels tell us the opposite.

So we offer our comments on the major types of disabilities with misgivings. We do not want to make it seem that people who have disabilities are a particular kind of people, set apart from others. On the other hand we think that it is important for all people to know some basic things about disabilities.

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* From the book: What's the Difference? Teaching Positive Attitudes Toward People with Disabilities, by Ellen Barnes, Carol Berrigan and Douglas Biklen

Children, schoolmates, peers want and need to know. Yet they themselves have been damaged by the "mystery and mockery" surrounding disabilities. to compensate, they need their questions answered honestly, directly, seriously. But, most of all, they need the chance to observe and emulate adults who are, themselves, conserned and compassionate about and with other people.

There are ongoing controversies conserning how various disabilities should be grouped. For example, many consider epilepsy a health impaired, others as a developmental disability. Some agencies consider autism a language disorder, others classify it as a kind of emotional disturbance. Still other question the usefulness of the term altogether. We do not defend any of the categories which are identified in this manual. We have simply used the current classification as defined by the Bureau for the Education of the Handicapped.

BEING AT EASE WITH HANDICAPPED CHILDREN

Fact Sheet

What to focus on?

For years handicapped people have been segregated from the rest of society as if they were truly different from non-handicapped people. Because of such federal legislation as Public Law 94-142 (the Education for All Handicapped Children Act of 1975) and Section 504 of the Vocational Rehabilitation Act Amendments of 1973, individuals who have handicaps are being integrated into the mainstream of education, employment, and community activities. It is sad that attitudes cannot be legislated too, but fears and anxieties toward those who are different cannot be decreed illegal. It is hoped that the present generation, growing up in situations where people with handicaps are a natural part of school and community life, will put to rest forever the notion that people with handicaps are "different."

However, for those people who have never known a handicapped person, and are suddenly faced with the new experience of having a disabled child in their classroom, scout troop, or community activity, it helps to focus on the fact that a child with a handicap is a child first. A child with a handicap has many attributes, such as brown hair, brown eyes, a turned up nose, an inability to hear, and so forth. By thinking of a child's disability as just one of his many characteristics, the anxiety often anticipated when a youngster with a handicap is scheduled to join a program can be greatly reduced.

What special treatment should be given?

Children with handicaps need to be treated, as much as possible, like any other child. It is unfair to the child when he or she is not allowed to compete. The world at large is mainly inhabited by people with the ability to see, to hear, to speak, and to move about freely. Children with handicaps need to practice meeting the standards of the "normal" world while they are growing up so they can gain confidence and independence.

How can one help but feel sorry for children with handicaps?

If you perceive the disabled child as someone to be pitied, someone from whom little should be expected or demanded, probably little will come. If, on the other hand, you expect the child to succeed and grow, to learn to act independently, then chances are good that the child will become a successful, growing, independent student.

How should frustrations or temper tantrums be handled?

Such problems should be handled the same way they would be handled if the child did not have a handicap. It is easy to assume that disabled people exist in a continuous state of frustration. This is not true. Of course disabled children may feel frustrated at times. These frustrations should be handled with good sense, remembering that a certain amount of frustration is healthy and promotes growth but that too much frustration can be defeating.

How should you respond to everyday accomplishments?

It is a joy to see a child with a handicap able to do the same things that other children do, such as read, play on the jungle gym, or go through the lunch line. It is important, however, to distinguish between accomplishments that are attained with about the same degree of effort that is required from most children, and those accomplishments that really represent a challenge to the handicapped child. If people react to ordinary accomplishments that were not particularly difficult to attain as if they were extraordinary, children can develop unrealistic views of themselves—either an inflated view of their capabilities and accomplishments, based on the continual amazement elicited from others, or a deflated view, based on the obviously limited expectations others hold for children with handicaps. On the other hand, encouragement and reinforcement should be expressed when youngsters accomplish tasks made difficult by their specific disabilities, for example, dressing for a child with cerebral palsy.

How much help should be given?

One of the benefits of mainstreaming is that children can help their disabled classmates. But too much help can become a hindrance if it robs the child of opportunities to learn and practice independence. Generally if a child cannot handle some procedure or material, she or he should be taught how to do it if at all possible.

Do children with communication problems also have problems in thinking?

One disability that people have trouble coping with involves speech and language. Whether the communication impairment results from a physical disability such as cerebral palsy or a speech handicap such as stuttering, the listener tends to anticipate what the disabled person is trying to say and not allow the person the time she or he needs to communicate. It is easy to mistakenly perceive people who have severe communication disabilities as also having impaired intelligence, because of their simple, poorly articulated speech. It is a natural tendency to respond to this kind of language pattern with a simplification of your own speech. This should be avoided. Individuals who have problems expressing themselves, unless they are also hearing impaired, generally have no problem understanding normal, complex language.

Isn't there anything special that needs to be done?

There are special considerations that can be helpful to children with specific disabilities. For example, keep in mind that children who have visual impairments depend on what they hear and touch to bring them information about their surroundings. Provide opportunities for visually impaired children to handle things that children with normal vision can simply look at. It is also helpful to describe new people, things, and events as they come into the child's environment. Allow time for the child to ask questions about what is going on.

Children who have hearing impairments or who are deaf must depend on sight for most of their knowledge. Make sure the hearing impaired child can see the face of whoever is speaking, since many cues are picked up through lipreading and facial expression. Arrange for seating near the teacher or leader. Do not assume that a youngster understands you just because you have his or her attention. Ask whether you have been understood.

Children who have a mental retardation problem can get along better when directions are short and clearly stated. Break down tasks into a series of steps that can be completed in sequence. Maintain a routine, teach new procedures, and give time for practice.

Youngsters with orthopedic impairments should be asked whether they need help and, if so, what kind. Do not assume the child needs more help than he asks for.

Note: Much of the information in this fact sheet was based on "Questions Teachers Ask," a chapter in the publication, *Supporting Visually Impaired Students in the Mainstream*, by Glenda J. Martin and Mollie Hoben, 1977. Available from: The Council for Exceptional Children, 1920 Association Drive, Reston VA 22091. ($3.00)

RESOURCES

People . . . Just Like You: About Handicaps and Handicapped People (an Activity Guide). The activity guide contains 24 suggested activities to improve the understanding and attitudes of children in grades K-12 toward persons with handicaps. Available from: Committee on Youth Development, The President's Committee on Employment of the Handicapped, Washington DC 20210. (Free)

TEACHING Exceptional Children in All America's Schools—A First Course for Teachers and Principals, by Maynard C. Reynolds and Jack W. Birch, 1977. Describes the behavior characteristics of children with various disabilities; explains the physical nature of the impairment; and provides suggestions on how to teach children who have different handicaps. Available from: The Council for Exceptional Children, 1920 Association Drive, Reston VA 22091. ($15.00)

What's the Difference? Teaching Positive Attitudes Toward People with Disabilities, by Ellen Barnes, Carol Berrigan, and Douglas Biklen, 1978. A book of activities for adults and children that fosters contact, empathy, information and responsive behavior toward disabled people. Available from: Human Policy Press, P.O. Box 127, University Station, Syracuse NY 13210. ($6.00)

ERIC A product of The ERIC Clearinghouse for Handicapped and Gifted Children
1920 Association Drive, Reston, Virginia 22091
1978

Professional Disciplines: Roles & Responsibilities

Sylvia Richardson, M.D.

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Early identification and remediation of children with handicapping conditions often requires a multidisciplinary approach, including representatives of pediatrics, neurology, psychology, speech-language pathology, special education, and frequently psychiatry. The physician must understand the unique contribution of each discipline. It is generally the responsibility of the physician to integrate the reports from related specialists and to interpret the integrated formulation to parents in terms they can understand.

Psychologist - Licensed

A psychologist conducts screening, diagnosis, and treatment of people with social, emotional, psychological, behavioral, or developmental problems. There are many different kinds of psychologists. A child with school problems would probably be seen by a school psychologist or a child psychologist.

Psychologists may ask children questions, observe them at play, ask the parents questions, and observe the children interacting with the parents. They may choose to administer standardized tests to assess children's cognitive abilities, academic skills, and adaptive behavior (ability to use language, to play with others, and to do things independently). Psychologists sometimes use play activities to understand and treat children. At times these specialists may want to talk with the whole family to help with problems they might have concerning a particular child. Psychologists can also help to determine appropriate educational programs and activities.

Audiologist - Licensed and/or Certified

An audiologist conducts screening and diagnosis of hearing problems, and may recommend a hearing aid or suggest resources for people with hearing handicaps.

The audiologist can also be called upon to answer questions in the following areas: the nature of a child's hearing loss, what the child can and cannot hear or perceive, the usefulness of a hearing aid, the care of a hearing aid, and the availability of special programs for children with hearing impairment.

Speech-Language Pathologist - Certified and/or Licensed

A speech-language pathologist conducts screening, diagnosis, and treatment of children and adults with communication disorders. This person may also be called a speech clinician or speech therapist.

The speech-language pathologist will also assist parents, teachers and other specialists by providing information about the nature and process of language acquisition and by working with them to establish a setting in which the child will have a maximum opportunity to learn these skills and where obstacles to learning will be minimized. The speech-language pathologist is by training equipped to deal with both speech (articulation, voice and fluency) and language problems.

Nutritionist

A nutritionist evaluates a person's food habits and nutritional status. This specialist can provide advice about normal and therapeutic nutrition, and information about special feeding equipment and techniques to increase a patient's self feeding.

Occupational Therapist - Licensed

An occupational therapist evaluates and treats children who may have difficulty performing self-help, play or school-related activities, with the aim of promoting self-sufficiency and independence in these areas. Evaluation and therapy for sensory integration is also provided.

Physical Therapist - Licensed

A physical therapist evaluates and plans physical therapy programs and directs activities for promoting self-sufficiency primarily related to gross motor skills such as walking, sitting, and shifting position. He or she also helps people with special equipment used for moving such as wheelchairs, braces and crutches.

Social Worker

A social worker provides services for individuals and families experiencing a variety of emotional or social problems. This may include direct counseling of an individual, family or group; advocacy; and consultation with preschool programs, schools, clinics, or other social agencies.

Optometrist

An optometrist examines the eyes and related structures to determine the presence of visual problems and/or eye disease, and to evaluate a child's visual development. She/he may also provide developmental visual-motor training.

Special Education Consultant for Visually Handicapped Children

Local, intermediate, county, or state department of education usually employ a specially trained teacher of visually handicapped children. This professional may be known as an itinerant teacher, resource teacher, or teacher-consultant of visually handicapped children. In most states this person is responsible for planning and implementing long-range plans for visually handicapped children.

Special Education Teacher of the Hearing Impaired

This special education teacher has advanced training in teaching hearing impaired children. He or she evaluates and works with these children in clinics, special schools, special classes, regular classrooms, or home settings.

In special classes, he or she works with hearing impaired children to help them develop listening, speech, language, academic and social skills. He or she may also instruct parents and teachers how to communicate effectively with the child and how to encourage the development of the child's own skills.

Special Education Teacher for Learning Disabled Children

Specially trained teachers of learning disabled children are usually employed by local, intermediate, county or state departments of education. They function as L.D. tutors, resource tutors, or special education teachers. In most states they are responsible for planning and implementing long-range plans for learning disabled children.

Notes to Trainer: This section can be geared to trainees' level of awareness. It would be helpful to invite local specialists from various disciplines to field questions.

Resources:
- Local specialists
- Handouts. (Those attached are optional. You may prefer others)

INFORMATION FROM . . . .

CLOSER LOOK

A Project of the Parents' Campaign for Handicapped Children and Youth

Box 1492
Washington, D.C. 20013

INTO THE MAINSTREAM

Classrooms are changing. Now, for the first time, many children with handicaps are working, learning, and playing side-by-side with their non-handicapped peers. With the mandate of P.L. 94-142 that disabled children be educated in the "least restrictive environment", youngsters who once would have been placed in separate special programs are joining the education mainstream.

Because this is a new experience for the children — and often for their teachers — some information and preparation can be very useful. Teachers are discovering that everyone can benefit from learning projects designed to teach non-disabled children about life in a wheelchair, or without vision, or without hearing. We would like to tell you of several "awareness" programs that have been used successfully in public schools. They are relatively inexpensive, easy to replicate, and adaptable to most school settings.

Programs

COUNT ME IN
The PACER Center
Parent Advocacy Coalition for Educational Rights
4701 Chicago Avenue South
Minneapolis, Minnesota 55407

Count Me In teaches children about disabilities and about understanding handicapped children through trained volunteers, who present puppet shows about handicaps to preschool and school age children. For more information on how you can create a similar program in your community, write to PACER.

THE EXCEPTIONAL EXPERIENCE
Marilyn Machkowsky, Marla Colarusso, Co-Directors
Exceptional Experiences Resources, Inc.
Hogan Regional Center
P.O. Box A
Hathorne, Massachusetts 01937

Originally funded by the Massachusetts Department of Education to prepare for integration of handicapped children, this program can be used with students, with teachers as in-service training, and by community groups. Handbooks and other materials on producing awareness programs in schools are available.

THE HANDICAPPED AWARENESS PROGRAM
Darline Handley
CCHC Program Coordinator
Coordinating Council for Handicapped Children
407 South Dearborn Street, Room 680
Chicago, Illinois 60605

Informal presentations are given by people who have disabilities and talk with student audiences about their limitations, their self-help skills and how they cope with daily living. They also talk about their activities, special talents and achievements, to round out a picture of disabled persons as people who can be understood, accepted, and appreciated as individuals. Write to the Council for suggestions on creation of awareness programs in your community.

LET'S BE FRIENDS
Team of Advocates for Special Kids (TASK)
8100 Garden Grove Boulevard
Garden Grove, California 92641

For elementary schools, the program team brings two dolls, one handicapped, who are shown in a play session. They talk about the doll's disability and play games, modifying them so that both dolls can participate. Afterward, the children may examine some of the special aids that have been brought along as exhibits, such as braille books or hearing aids. LET'S BE FRIENDS includes a lecture series suitable for high school classes. An information packet is also available.

Films

Most organizations concerned with handicapped people have annotated film listings available free of charge. National offices of parent groups are also a good source of film information. Although we cannot list all the films on awareness, we have found those below to be especially valuable. All the films we have listed may be borrowed for the cost of return postage from: Handicapped Learner Materials Distribution Center, Audio-Visual Center, Indiana University, Bloomington, Indiana 47405.

A DIFFERENT APPROACH. Useful for junior and senior high school students as well as adults, this uses a humorous film-within-a-film to make its point about hiring disabled workers. To purchase, write: South Bay Mayor's Committee for Employment of the Handicapped, 2409 N. Sepulveda Boulevard, #202, Manhattan Beach, California 90266. May also be borrowed for the cost of return postage from: Modern Talking Picture Service, 2000 L Street, N.W., Room 107, Washington, D.C. 20036.

FEELING FREE. Based on the television series of the same name, this has been edited into fourteen-minute versions for classroom use. Disabled children are shown playing games, enjoying recreational activities — and talking about what it's like to be handicapped. To purchase, write: Scholastic's Feeling Free, 904 Sylvan Avenue, Englewood Cliffs, New Jersey 06732.

PEOPLE YOU'D LIKE TO KNOW. Ten short films that feature children with disabilities, showing them at home, at school, and with friends. To purchase, write: Encyclopaedia Britannica Educational Corporation, 425 North Michigan Avenue, Chicago, Illinois 60611.

As mainstreaming brings more disabled children into regular classrooms, and as they begin to be better acquainted with their non-disabled classmates, there will be less need for special awareness efforts and programs. Meanwhile, they can go a long way toward smoothing the path for all concerned.

PUBLICATIONS LIST

REGIONAL REHABILITATION RESEARCH INSTITUTE
ON ATTITUDINAL, LEGAL AND LEISURE BARRIERS

George Washington University
1828 L St., N.W., Suite 704
Washington, D.C. 20036
Phone: (202) 676-6377

The Regional Rehabilitation Research Institute on Attitudinal, Legal & Leisure Barriers (RRRI-ALLB) is located at George Washington University, Washington, D.C. and is funded by the National Institute of Handicapped Research, Dept. of Education. The RRRI-ALLB conducts research and prepares materials for rehabilitation professionals and the general public on attitudes related to disability. The following list of publications can be useful to both professionals and the general public in reducing attitudinal barriers toward people with disabilities.

The last page of this list is your order form. Prices are subject to change without notice. Payment must accompany your order. Sorry, we cannot discount bulk orders.

*** BARRIER AWARENESS SERIES ***

[illegible] series of booklets dealing with attitudes toward disability. Can be used independently or as a set. Each booklet focuses on a different set of attitudinal barriers. Written for the general public.

- THE INVISIBLE BATTLE: ATTITUDES & DISABILITY -- Attitudes of nondisabled people toward disabled people in general. Price: $ .50
- BEYOND THE SOUND BARRIER -- Attitudes toward people with hearing impairment or deafness. Price: $ .50
- FREE WHEELING -- Attitudes toward people who use wheelchairs. Price: $ .50
- COUNTERPOINT -- Attitudes of disabled people toward nondisabled people. Companion to The Invisible Battle. Price: $ .50
- DIGNITY -- Attitudes toward people with mental retardation. Price: $ .50
- OVERDUE PROCESS: PROVIDING LEGAL SERVICES TO DISABLED CLIENTS -- Attitudes of legal professionals toward disabled people and how those attitudes affect a disabled person's access to the legal system. Contains resource listings of relevant journals and organizations. Price: $ .50
- SENSE ABILITY -- Attitudes toward people who are blind or partially sighted. Price: $ .50
- INSIDE OUT -- Attitudes toward people with hidden disabilities (e.g., epilepsy, diabetes, cancer). Price: $ .50

*** ANNOTATED BIBLIOGRAPHIES ***

- BURNOUT AND THE SOCIAL SERVICE PROFESSIONS: AN ANNOTATED BIBLIOGRAPHY (by Makas). 25 listings, 1980. Price: $1.00

- CLIENT & COUNSELOR ATTITUDES IN A REHABILITATION SETTING: A SELECTED ANNOTATED BIBLIOGRAPHY (by Makas). 59 listings, 1979. Price: $1.00

- ATTITUDES & DISABILITY: A SELECTED ANNOTATED BIBLIOGRAPHY 1975-1977 (by Panieczko). 83 pages, 1978. Price: $3.00

- LAW & DISABILITY: A SELECTED ANNOTATED BIBLIOGRAPHY OF ARTICLES IN LEGAL PERIODICALS 1976-1978 (by Topp & Cornelius). 208 listings, 1979. Price: $3.00

*** GUIDES ***

- A LISTING OF DISABILITY-ORIENTED CONSUMER AND SUPPORT ORGANIZATIONS (by Cornelius). 87 listings, 1979. Price: $1.00

- HANDBOOK OF EMPLOYMENT RIGHTS OF THE HANDICAPPED: SECTIONS 503 & 504 OF THE REHABILITATION ACT OF 1973 (by Hermann & Walker). Written for the layperson. 87 pages + glossary. Price: $3.00

*** SEXUALITY & DISABILITY ***

- WHO CARES? A HANDBOOK ON SEX EDUCATION AND COUNSELING SERVICES FOR DISABLED PEOPLE (by Chipouras, Cornelius, Daniels & Makas). 234 pages, including resource appendices. Final report of the Sex & Disability Project. Written for disabled consumers, counselors, service providers, trainers, educators, and administrators. 1979. Price: $10.00

- SEXUALITY & DISABILITY: A SELECTED ANNOTATED BIBLIOGRAPHY. Second Edition (by Cornelius, Makas & Chipouras). 413 listings, 1979. Price: $3.00

*** REPORTS ***

- FOCUS ON RESEARCH: RECREATION FOR DISABLED INDIVIDUALS. Report of national needs assessment on recreation related to people with disabilities. Includes research topics and background information. 165 pages, 1980. Price: $4.00

- REHABILITATION COUNSELOR-CLIENT STUDY: FINAL REPORT (by Makas). An analysis of a survey on rehabilitation client attitudes toward certain counselor characteristics. 56 pages, 1980. Price: $2.00

*** NEWSLETTER ***

- RE: SEARCH -- A bi-monthly publication on various topics of interest to the rehabilitation community and news about the RRRI-ALLB. Price: Free

-- July 15, 1980

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UNIT III: IDENTIFICATION

GOALS AND OBJECTIVES

Identifying Children and Youth with Handicapping Conditions

Purpose:

To examine indicators of handicapping conditions, the need for coordinated services for disabled children and youth, and to foster positive attitudes toward disabled children and youth.

Specific Objectives:

At the conclusion of this session, participants should:

1. Recognize the need to be sensitive to and accept the need for early intervention strategies for children exhibiting handicapping conditions.
2. Recognize the handicapping conditions included in PL 94-142.
    a. Understand the difference between disabilities and handicaps.
    b. Understand the scope of handicapping conditions to include:
        (1) severely handicapped
        (2) mildly and moderately handicapped
        (3) high risk children and youth
3. Recognize the indicators of the following handicapping conditions:
    a. Visual impairments
    b. Hearing impairments
    c. Orthopedic impairments
    d. Speech impairments
    e. Mental retardation
    f. Severe emotional disturbances
    g. Learning disabilities
    h. Health impairments
    i. High-risk conditions
4. Recognize and accept the need for coordinated services for disabled children and youth.

Unit III

Identification

by

Anthony Bashir, Ph.D.

HANDICAPPING CONDITIONS AND P.L. 94-142

> But always the surest guarantee of change and growth is the inclusion of living persons in every stage of an activity. Their lives, their experiences and their continuing responses - even their resistance - infuse with life any plan which if living participants are excluded, lies on the drawing board and loses its reality,
>
> Margaret Mead

I. P.L. 94-142: Summary of Decision Model

- A. Referral: Referral is made specific to a set of chief complaints or concerns.
    1. Consent for testing from parent or legal guardian
    2. Decisions for assessments on the basis of chief complaint or concerns.
    3. Additional Assessments as may be required

- B. Meeting of the Evaluation Team
    1. Sharing of assessment findings
    2. Integration of findings
    3. Determination of the presence or absence of a handicapping condition

- C. Service Needs: The Individual Educational Plan
    1. Educational Placement
    2. Clinic-educational needs

- D. Individual is placed in the appropriate setting

- E. The Individual Educational Plan is implemented
  The Individual Educational Plan is reviewed

- F. Annual Review
    1. The Evaluation Team reconvenes
    2. Information concerning present status of child is shared
    3. Appropriateness of the Individual Educational Plan and placement is discussed
    4. Revision of the Individual Education Plan and Service Plan

- G. Individual is placed in the appropriate setting

II. P.L. 94-142: The Handicapping Conditions

The following are considered handicapping conditions within the law

- A. Deaf
- B. Hard-of-Hearing
- C. Mentally Retarded
- D. Orthopedically impaired
- E. Other health impaired
- F. Seriously Emotionally Disturbed
- G. Specific Learning Disabilities
- H. Speech impaired
- I. Visually Handicapped

III. Some Aspects of Handicapping Conditions

A. The Deaf and Hearing Impaired

"Deaf" means a hearing impairment which is so severe that the child's hearing is non-functional for purposes of educational performance" "Hard of hearing" means a hearing impairment, whether permanent or fluctuating which adversely affects a child's educational performance, but which is not included under . . . deaf . . ." P.L. 94-142

1. Etiology
2. Classification of Hearing impairments
    - a. types
    - b. degree
    - c. age of onset

3. Assessment

4. Habilitation
    - a. Early identification and early programs: Auditory Approaches
    - b. Debate: Oral vs. Total Communication
    - c. Amplification
    - d. Speech and language Acquisition
    - e. Implications for learning in school: Program Options
    - f. Implications for psychological development
    - g. Implications for life planning
        - (1) family
        - (2) peers
        - (3) vocation

5. Behavioral Indices for High Risk: Some things to consider
    - a. High Risk Indicators, e.g., Rubella, Anoxia, prematurity, Rh-incompatibility, meningitis, encephalitis, etc.
    - b. Genetic: Familial History

c. Fluctuating attention to sound or speech
d. History of chronic middle ear disease
e. Irritability - Hyperactivity
f. Decreased Localization Response
g. Delay in onset of language or developmental alteration in language and speech acquisition
i. Variability in response to speech from group to individual setting

B. Mental Retardation

"Mentally Retarded" means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance" P.L. 94-142

1. Definition: Marks the necessity of three criteria in determining mental retardation, i.e.,

    a. impairment of intelligence
    b. The manifestation in the "Developmental Period"
    c. Impairment in adaptive behavior, i.e., Learning Skills. Social realization, economic independence/ dependence

Classification: Must consider these areas in individual planning and programming needs

2. Etiology

    a. Genetic Causes
    b. Pre-natal, neonatal, postnatal problems
    c. Infectious Diseases
    d. Nutritional aspects

3. Classification

    a. Range of Severity
    b. Differential Aspects of Deviant Functions

        (1) Cognitive skills
        (2) Judgement and reasoning
        (3) Self-help skills
        (4) Motor abilities
        (5) Communication skills
        (6) Socialization
        (7) Academic learning
        (8) Family-Environment interaction

4. Assessment

   a. Assessment of an individual for the determination of mental retardation is by nature complex and requires the use of a multidisciplinary approach
   b. Instruments of intellectual assessment and the problem of culture-free testing
   c. The sociological implications of assessment

5. Educational management

   a. Mainstreaming and other educational provider models, e.g., self-contained, resource rooms, tutorials, special therapies, etc.
   b. The family setting
   c. Social aspects of educational management
   d. Vocational Issues

6. Behavioral Indices for High Risk: Some things to consider

   a. High Risk Indicators (See Etiology B,2)
   b. Delayed acquisition of motor milestones
   c. Delayed acquisition of speech and language skills
   d. Inconsistent patterns in the development of attention skills, eye-hand coordination activities, comprehension of language, significant reduction in sentence production and vocabulary growth, etc.
   e. Decrease rate and effectiveness in academic learning

C. Orthopedically Impaired

"Orthopedically impaired" means a severe orthopedic impairment which adversely affects a child's educational performance. The term includes impairment caused by congential anamoly (e.g., club foot, absence of some member, etc.), impairment caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.) and impairments from other causes (.e.g, fractures of burns which cause contractures, amputation, cerebral palsy, etc.)." P.L. 94-142.

There is a need to clearly identify the differences among the disabilities described under the collective term "Orthopedically impaired". The areas of functioning such as sensory, intellectual, motoric, emotional and school growth are differentially involved. Consequently, care must be taken in the assessment and educational planning for a child with, for example, clubfoot and the child with significant non-progressive central nervous system disorder as manifested in the child with cerebral palsy.

1. Etiology

   a. Embryo dysgenesis
   b. Prenatal, natal, post-natal events

  - c. Infectious diseases
  - d. Acquired causes

2. Classification

  - a. Type of impairment
  - b. Specification of site of involvement
  - c. Specification of impairment in terms of impact on
    - (1) Acquisition of motor patterns
    - (2) Kind of movement disorder
    - (3) Effects on postural tone and postural stability
    - (4) Effects on range of motion
    - (5) Effects on the acquisition of functional motor skills and independence of motor based functions e.g., walking, feeding, pressing, writing, etc.
  - d. Severity as a function of independence and constraints on a development of independence
  - e. Age of onset

3. Assessment: The determination of need must be by a multidisciplinary team in which integration of medical, clinical and educational assessments occurs. Those individualsproviding assessments should be chosen on the basis of professional training and experiences with individuals evidencing a diverse range of orthopedic conditions.

4. Habilitation

  - a. Early Intervention Programs: the need for having holistic approaches to the problem, especially with cerebral palsy and spina bifida
  - b. Accomodation needs
    - (1) Physical needs, brauna and prosthetic applicances
    - (2) Motor planning training and facilitation
    - (3) Adaptive equipment and adapting of equipment
    - (4) Environmental, e.g., toileting, feeding, grooming
    - (5) Architectural accomodations
    - (6) Augmentative Communications Systems
  - c. Curricular needs and provider models
  - d. Social-vocational needs and appropriate planning
  - e. Planning for disruptions in educational process due to need for medical-surgical intervention

5. These conditions are a result of congenital anomalies, accidents or as a result of disease processes and are known form birth, early infancy or noted as a consequence of severe illness

6. The above discussion will aslo apply to those children with "other health impairments". An approach which integrates the unique and differing ways various diseases affect a child's life and consequently his/her availability as a learner must be used. There is a need frequently to review a child's status as aspects of disease impinge upon life. The impact of chronic illness and acute episodes must be realistically managed in all aspects of a child's life with family, school and social attention.

D. Seriously emotionally disturbed.

"Seriously emotionally disturbed" means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree: an inability to learn which cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behaviors or feelings under normal circumstances; a general or pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms, or fears associated with personal or school problems. The term includes children who are schizophrenic or autistic. The term does not include children who are socially maladjusted but not emotionally distrubed". P.L. 94-142.

1. Etiology

    a. Genetic
    b. Biochemical basis
    c. Environmental/Interactional Basis

2. Classification

    a. Severity: as a function of perceived social and inter-personal deviancy and loss of functional independence
    b. Types: Ranging from chronic anxiety, depression, aggression , autism, schizophernia.
    c. Age of onset

3. Assessment:

    a. To establish current levels of functioning, e.g., cognitive, emotional, academic, and social
    b. To evaluate maintaining factors that interfere with the person's resolution of conflict

   c. To determine the appropriate milieu for the individual that will facilitate emotional and cognitive growth

4. Habilitation

   a. Mileau setting; residential setting; other service models
   b. Psychiatric/Psychological Therapy
   c. Work with the family

5. Behavioral Indices of High Risk: Some considerations

   a. The inability to relate or enter into reciprocal activities
   b. The deterioration of family relationships
   c. The inability to establish or the deterioration of peer relationships
   d. Inappropriate or bizarre content of communication
   e. Behavioral Disruption, e.g., significant aggressive behavior, disruption in sleep patterns, regression in bowel and or bladder control, significant changes in feeding behavior
   f. Irrational or exagerrated fears
   g. Periods of unexplained saddness, crying, or withdrawal or lethargy
   h. Periods of agitated behaviors, e.g., inattention, preoccupation (day-dreaming), distractibility
   i. Periods of "ritualistic" behaviors
   j. Inability to tolerate change or alteration of routines, i.e., over reliance on routines
   k. excessive use of substances

E. Specific Learning Disabilities

"Specific Learning Disabilities means a disorder in one or more of the basic psychological processes involved in understanding or or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, of motor handicaps, of mental retardation, or of environmental cultural, or economic disadvantages." P.L. 94-142.

Learning disabilities is a general term that refers to a group of differing disorders. These disorders are realized as significant difficulties in the acquisition and use of one or more of the following functions: listening, speaking, reading, writing, reasoning and mathematical abilities. Individuals with such disabilities may also evidence problems in their quality to self-regulate behaviors and demonstrate altered patterns of social perception and social interaction (NKLD: Position paper on Learning Disabilities: Issues on Definition, 1981).

1. Etiology

   a. Genetic factors
   b. Anatomical differences of the central nervous system (CNS)
   c. Neuromaturational delay
   d. Neurochemical/metabolic imbalance
   e. Severe nutritional deficiency
   f. Trauma to the CNS and other acquired causes

2. Classification

   a. Type of presenting disability
   b. Severity of presenting disability

      (1) Disorders of listening
      (2) Disorders of oral expression
      (3) Disorders of written expression
      (4) Deficits in acquiring basic reading skills
      (5) Deficits in reading comprehension
      (6) Deficits in conceptual functioning and meaning
      (7) Deficits in mathematical calculation

3. Assessment

Assessment: The goal of assessment is the determination of strength and weakness patterns and learning styles. As they relate to the individual's learning disability. Provision of assessment should be a multidisciplinary team.

4. Habilitation

   a. Selection of appropriate educational setting, e.g., mainstreaming with supportive services, self-contained classroom, the use of the resource room
   b. Specific therapies
   c. Psychological/Counselling Services
   d. Pre-vocational and vocational planning

5. Behavioral Indices of High Risk: Some considerations

   a. History of inattention, distractibility, impulsivity.
   b. History of hyperactivity

c. Presence of problems with eye-hand coordination
d. Problems in orientation and laterally
e. Presence of language disorders

F. Communication Disorders

"Speech impaired" means a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, which adversely affects a child's educational performance." P.L. 94-142.

1. Etiology: Disorders of communication have heterogenesis etiologies.

    a. Structural causes
    b. Central and peripheral nervous systems basis
    c. Sensory basis
    d. cognitive basis
    e. emotional basis
    f. Mislearning as a basis
    g. Environmental interaction as a basis

2. Classification

    a. Types

        (1) Resonance Disorders: Deficits arising from a disruption in normal oronasal sound balance and most commonly heard or heard as hypernasality or hyponasality

        (2) Voice disorders: Deviations in the quality, pitch, or loudness of the voice. The basis of these deficits may be physiological and/or psychological in nature

        (3) Fluencey disorders: Disruptions in the natural flow of connected speech. The most common form of the disorder is stuttering.

        (4) Articulation Disorders: Problems in speech sound production

        (5) Language Disorders: Disruptions in the person's ability to comprehend and/or use the symbol systems of language; these individuals evidence problems in the use of language for purposes of social dialogue; in addition the majority of these individuals will evidence academic learning problems

    b. Severity
    c. Age of onset

3. Habilitation

    a. Early intervention programs
    b. Pre-school and school-based self-contained language classes
    c. Psychological/counselling support systems
    d. Family support systems
    e. Medical-surgical management
    f. Specific speech-language therapies
    g. Audiological assessments and management

4. Behavioral Issues for High-Risk: Some considerations

    a. Hearing impairment
    b. Significant history of chronic middle ear disease in the first two years of life
    c. Structural disorders of the oral cavity, e.g., cleft lip and palate
    d. Neurological disease or disorders
    e. Lack of two-word phrases by 2 year, 6 months
    f. Lack of comprehension of name, body parts and common objects by 2 years
    g. Lack of sentences by 3 years

G. Visually Handicapped

"Visually Handicapped" means a visual impairment which after correction, adversely affects a child's educational performance. The team includes both partially seeing and blind children." P.L. 94-142.

1. Etiology

    a. Infections
    b. Injuries
    c. Escessive Oxygen
    d. Tumors
    e. In association with known developmental disabilities
    f. prenatal causes, e.g., rubella

2. Classification

    a. Site of lesion
    b. Type of disorder
    c. Severity of disorder
    d. Age of onset

3. Assessment
    - a. Medical Aspects
    - b. Educational Aspects
        - (1) Academic
        - (2) Ambulation
    - c. Personal and social assessment

4. Habilitation
    - a. Early intervention
        - (1) Medical management
        - (2) Education management
    - b. Type of educational setting
    - c. Ambulation and parpatetic training
    - d. Braille: its teaching and use
    - e. Pre-vocational and vocational aspects
    - f. Personal and social assessment

5. Behavioral Issues for High Risk: Some considerations
    - a. Early signs: not associated with known medical concerns
        - (1) Appearance of strabismus after 2 mos.
        - (2) Wandering or uncoordinated eyes
        - (3) Nystagmus
        - (4) Holding items close for visual inspection
        - (5) Locking head to look at objects or people
        - (6) Disregarding objects in the peripheral field
        - (7) Poking, rubbing of eyes
        - (8) Flicking fingers at periphery of visual fields

(9) Light staring in reference to people

b. In the older child

  - (1) Complaints of eyes itching, burning, etc.
  - (2) Complaining of blurred vision, not being able to see the board in school
  - (3) Holding objects or books close for visual inspection
  - (4) Cocking head to look at objects or people
  - (5) Occular-motor problems

UNIT III: IDENTIFICATION

RESOURCES

- Fact Sheet about Handicapping Conditions and the People It Affects.
- Chart of Normal Development: Infancy to Six Years of Age, from Mainstreaming Preschoolers, the Head Start Bureau.
- Diagnostic Criteria for Reporting Handicapped Children in Head Start, Seventh Annual Report of the U.S. Department of Health, Education, and Welfare to the Congress of the United States on Services Provided to Handicapped Children in Project Head Start, February 1980.
- Observational Checklists for:
  Motor Problems
  Health Problems
  Emotional Behavior Problems
  Mental Retardation*
  Speech and Language*
  Learning Disabilities*
  Hearing*
  Visual*

  * Adapted from the series on Mainstreaming Preschoolers for the Head Start Bureau by the staff of CRC Education and Human Development, Inc.
- Fact Sheet - Learning Disabilities, by ERIC Clearinghouse on Handicapped and Gifted Children.
- Getting to Know Each Other, a reading list to help you learn more about children and youth who have handicaps, by CLOSER LOOK.
- Developmental Screening of Preschool Children: A Critical Review of Inventories Used in Health and Educational Programs, by Helene S. Thorpe, and Emmy E. Werner, published in Pediatrics, May 1974.
- Professional Competence and the Assessment of Exceptional Children, by Bennett, R. Journal of Special Education, in press.

FACT SHEET ABOUT HANDICAPPING CONDITIONS AND THE PEOPLE IT AFFECTS

- One in every ten Americans has a mentally retarded family member.*
- An estimated one to three percent of the United States population is believed to be mentally retarded--possibly 6.5 million people.*
- Wheelchair users--about 500,000 in the United States--have a variety of disabilities ranging from paralysis and nerve damage to muscle weakness and lack of coordination.
- In the United States, five in every ten thousand births will result in Kanner Syndrome, or "classic" autism.**
- Children who have many of the symptoms of autism, but are not "classic" autistic children, occur in fifteen out of every ten thousand births (this also includes related communication handicaps).**
- There are roughly sixty thousand autistic children under the age of eighteen in the United States.**
- There are more than eight million handicapped children in the United States.***
- More than half of the handicapped children in the United States did not get the right educational services.
- One million of the handicapped children in the United States were not in the public school system and did not go through school with non-handicapped classmates.
- One in eleven persons is handicapped.
- Over eleven million Americans ages 16-64 reported that they had permanent work disabilities in 1970.
- Disabilities increase with age.
- Thirty seven percent of disabled Americans ages 18-64 did not go beyond elementary school compared with eighteen percent of the general population.
- Eighty-five percent of the disabled did not go beyond high school compared with seventy-five percent of the general population.
- Only five percent of the disabled had some college education compared with eleven percent of the general population.

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* Information from the National Association for Retarded Citizens.

** Information from the National Society for Autistic Children.

*** Information from the President's Committee for Employment of the Handicapped.

- Higher proportions of disabled persons have never worked than persons in the general population.

Disability takes a variety of forms:*

- Twenty six percent of the disabled had cardiovascular disorders, including heart troubles and high blood pressure.
- Twenty five percent had muscular or skeletal conditions, including arthritis, rheumatism and back troubles.
- Ten percent had mental disorders, including mental retardation and mental illness.
- Nine percent had respiratory and related disorders, including asthma.
- Nine percent had disorders of the nervous system, including epilepsy, multiple sclerosis, and paralysis.
- Five percent had digestive disorders.
- Three percent had diabetes.
- Three percent had visual impairments.
- Ten percent had other and unspecified conditions. (It is estimated that deafness is the nation's most prevalent disability. However, no breakdown on deafness was included in the above profile).

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* U.S. Government Printing Office: 1980, 0-328-974/6518.

Source: Facts About Handicapped People, The President's Committee on Employment of the Handicapped, Washington, D.C., 20210.

From: Mainstreaming, Pre-schoolers, Head Start Bureau.

Chart of Normal Development: Infancy to Six Years of Age

The chart of normal development on the next few pages presents children's achievements from infancy to six years of age in five areas:

- motor skills (gross and fine)
- cognitive skills
- self-help skills
- social skills
- communication skills (understanding language and speaking language).

In each skill area, the age at which each milestone is reached *on the average* is also presented. This information is useful if you have a child in your class who you suspect is seriously delayed in one or more skill areas.

However, it is important to remember that these milestones are only average. From the moment of birth, each child is a distinct individual, and develops in his or her unique manner. No two children have ever reached all the same developmental milestones at the exact same ages. The examples that follow show what we mean.

By nine months of age, Gi Lin had spent much of her time scooting around on her hands and tummy, making no effort to crawl. After about a week of pulling herself up on chairs and table legs, she let go and started to walk on her own. Gi Lin skipped the crawling stage entirely and scarcely said more than a few sounds until she was 15 months old. But she walked with ease and skill by 9½ months.

Marcus learned to crawl on all fours very early, and continued crawling until he was nearly 18 months old, when he started to walk. However, he said single words and used two-word phrases meaningfully before his first birthday. A talking, crawling baby is quite a sight!

Molly worried her parents by saying scarcely a word, although she managed to make her needs known with sounds and gestures. Shortly after her second birthday, Molly suddenly began talking in two- to four-word phrases and sentences. She was never again a quiet child.

All three children were healthy and normal. By the time they were three years old, there were no major differences among them in walking or talking. They had simply developed in their own ways and at their own rates. Some children seem to concentrate on one thing at a time — learning to crawl, to walk, or to talk. Other children develop across areas at a more even rate.

As you read the chart of normal development, remember that children don't read baby books. They don't know they're supposed to be able to point out Daddy when they are a year old, or copy a circle in their third year. And even if they could read the baby books, they probably wouldn't follow them! Age-related development milestones are obtained by averaging out what many children do at various ages. No child is "average" in all areas. Each child is a unique person.

One final word of caution. As children grow, their abilities are shaped by the opportunities they have for learning. For example, although many five-year-olds can repeat songs and rhymes, the child who has not heard songs and rhymes many times cannot be expected to repeat them. All areas of development and learning are influenced by children's experiences as well as by the abilities they are born with.

Chart of Normal Development

	Motor Skills		Communication Skills	
	Gross Motor Skills	Fine Motor Skills	Understanding of Language	Spoken Language
0-12 Months	Sits without support. Crawls. Pulls self to standing and stands unaided. Walks with aid. Rolls a ball in imitation of adult.	Reaches, grasps, puts object in mouth. Picks things up with thumb and one finger (pincer grasp). Transfers object from one hand to other hand. Drops and picks up toy.	Responds to speech by looking at speaker. Responds differently to aspects of speaker's voice (for example, friendly or unfriendly, male or female). Turns to source of sound. Responds with gesture to **hi, bye-bye,** and **up,** when these words are accompanied by appropriate gesture. Stops ongoing action when told **no** (when negative is accompanied by appropriate gesture and tone).	Makes crying and non-crying sounds. Repeats some vowel and consonant sounds (babbles) when alone or when spoken to. Interacts with others by vocalizing after adult. Communicates meaning through intonation. Attempts to imitate sounds.
12-24 Months	Walks alone. Walks backward. Picks up toys from floor without falling. Pulls toy, pushes toy. Seats self in child's chair. Walks up and down stairs (hand-held). Moves to music.	Builds tower of 3 small blocks. Puts 4 rings on stick. Places 5 pegs in pegboard. Turns pages 2 or 3 at a time. Scribbles. Turns knobs. Throws small ball. Paints with whole arm movement, shifts hands, makes strokes.	Responds correctly when asked **where,** (when question is accompanied by gesture). Understands prepositions **on, in,** and **under.** Follows request to bring familiar object from another room. Understands simple phrases with key words (for example, **Open the door,** or **Get the ball**). Follows a series of 2 simple but related directions.	Says first meaningful word. Uses single words plus a gesture to ask for objects. Says successive single words to describe an event. Refers to self by name. Uses **my** or **mine** to indicate possession. Has vocabulary of about 50 words for important people, common objects, and the existence, nonexistence, and recurrence of objects and events (for example, **more** and **all gone**).

Cognitive Skills		Self-Help Skills	Social Skills
Follows moving object with eyes. Recognizes differences among people. Responds to strangers by crying or staring. Responds to and imitates facial expressions of others. Responds to very simple directions (for example, raises arms when someone says, **Come**, and turns head when asked, **Where is Daddy?**).	Imitates gestures and actions (for example, shakes head no, plays peek-a-boo, waves bye-bye). Puts small objects in and out of container with intention.	Feeds self cracker. Holds cup with two hands. Drinks with assistance. Holds out arms and legs while being dressed.	Smiles spontaneously. Responds differently to strangers than to familiar people. Pays attention to own name. Responds to **no**. Copies simple actions of others.
Imitates actions and words of adults. Responds to words or commands with appropriate action (for example: **Stop that. Get down**). Is able to match two similar objects. Looks at storybook pictures with an adult, naming or pointing to familiar objects on request (for example: **What is that? Point to the baby**).	Recognizes difference between **you** and **me**. Has very limited attention span. Accomplishes primary learning through own exploration.	Uses spoon, spilling little. Drinks from cup, one hand, unassisted. Chews food. Removes shoes, socks, pants, sweater. Unzips large zipper. Indicates toilet needs.	Recognizes self in mirror or picture. Refers to self by name. Plays by self. Initiates own play. Imitates adult behaviors in play. Helps put things away.

	Motor Skills		Communication Skills	
	Gross Motor Skills	Fine Motor Skills	Understanding of Language	Spoken Language
24-36 Months	Runs forward well. Jumps in place, two feet together. Stands on one foot, with aid. Walks on tiptoe. Kicks ball forward.	Strings 4 large beads. Turns pages singly. Snips with scissors. Holds crayon with thumb and fingers, not fist. Uses one hand consistently in most activities. Imitates circular, vertical, horizontal strokes. Paints with some wrist action. Makes dots, lines, circular strokes. Rolls, pounds, squeezes, and pulls clay.	Points to pictures of common objects when they are named. Can identify objects when told their use. Understands questions forms **what** and **where**. Understands negatives **no, not, can't,** and **don't**. Enjoys listening to simple storybooks and requests them again.	Joins vocabulary words together in two-word phrases. Gives first and last name. Asks **what** and **where** questions. Makes negative statements (for example, **Can't open it**). Shows frustration at not being understood.
36-48 Months	Runs around obstacles. Walks on a line. Balances on one foot for 5 to 10 seconds. Hops on one foot. Pushes, pulls, steers wheeled toys. Rides (that is, steers and pedals) tricycle. Uses slide without assistance. Jumps over 15 cm. (6") high object, landing on both feet together. Throws ball overhead. Catches ball bounced to him or her.	Builds tower of 9 small blocks. Drives nails and pegs. Copies circle. Imitates cross. Manipulates clay materials (for example, rolls balls, snakes, cookies).	Begins to understand sentences involving time concepts (for example, **We are going to the zoo tomorrow**). Understands size comparatives such as **big** and **bigger**. Understands relationships expressed by **if...then** or **because** sentences. Carries out a series of 2 to 4 related directions. Understands when told, **Let's pretend**.	Talks in sentences of three or more words, which take the form agent-action-object (**I see the ball**) or agent-action-location (**Daddy sit on chair**). Tells about past experiences. Uses "s" on nouns to indicate plurals. Uses "ed" on verbs to indicate past tense. Refers to self using pronouns **I** or **me**. Repeats at least one nursery rhyme and can sing a song. Speech is understandable to strangers, but there are still some sound errors.

Cognitive Skills		Self-Help Skills	Social Skills
Responds to simple directions (for example: **Give me the ball and the block. Get your shoes and socks**). Selects and looks at picture books, names pictured objects, and identifies several objects within one picture. Matches and uses associated objects meaningfully (for example, given cup, saucer, and bead, puts cup and saucer together). Stacks rings on peg in order of size. Recognizes self in mirror, saying, **baby**, or own name.	Can talk briefly about what he or she is doing. Imitates adult actions (for example, housekeeping play). Has limited attention span. Learning is through exploration and adult direction (as in reading of picture stories). Is beginning to understand functional concepts of familiar objects (for example, that a spoon is used for eating) and part/whole concepts (for example, parts of the body).	Uses spoon, spilling little. Gets drink from fountain or faucet unassisted. Opens door by turning handle. Takes off coat. Puts on coat with assistance. Washes and dries hands with assistance.	Plays near other children. Watches other children, joins briefly in their play. Defends own possessions. Begins to play house. Symbolically uses objects, self in play. Participates in simple group activity (for example, sings, claps, dances). Knows gender identity.
Recognizes and matches six colors. Intentionally stacks blocks or rings in order of size. Draws somewhat recognizable picture that is meaningful to child, if not to adult. Names and briefly explains picture. Asks questions for information (**why** and **how** questions requiring simple answers). Knows own age. Knows own last name.	Has short attention span. Learns through observing and imitating adults, and by adult instruction and explanation. Is very easily distracted. Has increased understanding of concepts of the functions and groupings of objects (for example, can put doll house furniture in correct rooms) part/whole (for example, can identify pictures of hand and foot as parts of body). Begins to be aware of past and present (for example: **Yesterday we went to the park. Today we go to the library**).	Pours well from small pitcher. Spreads soft butter with knife. Buttons and unbuttons large buttons. Washes hands unassisted. Blows nose when reminded. Uses toilet independently.	Joins in play with other children. Begins to interact. Shares toys. Takes turns with assistance. Begins dramatic play, acting out whole scenes (for example, traveling, playing house, pretending to be animals).

	Motor Skills Gross Motor Skills	Fine Motor Skills	Communication Skills Understanding of Language	Spoken Language
48-60 Months	Walks backward toe-heel. Jumps forward 10 times, without falling. Walks up and down stairs alone, alternating feet. Turns somersault.	Cuts on line continuously. Copies cross. Copies square. Prints a few capital letters.	Follows three unrelated commands in proper order. Understands comparatives like pretty, prettier, and prettiest. Listens to long stories but often misinterprets the facts. Incorporates verbal directions into play activities. Understands sequencing of events when told them (for example, **First we have to go to the store, then we can make the cake, and tomorrow we will eat it**).	Asks **when, how,** and **why** questions. Uses models like **can, will, shall, should,** and **might.** Joins sentences together (for example, **I like chocolate chip cookies and milk**). Talks about causality by using **because** and **so.** Tells the content of a story but may confuse facts.
60-72 Months	Runs lightly on toes. Walks on balance beam. Can cover 2 meters (6'6") hopping. Skips on alternate feet. Jumps rope. Skates.	Cuts out simple shapes. Copies triangle. Traces diamond. Copies first name. Prints numerals 1 to 5. Colors within lines. Has adult grasp of pencil. Has handedness well established (that is, child is left- or right-handed). Pastes and glues appropriately.	Demonstrates preacademic skills.	There are few obvious differences between child's grammar and adult's grammar. Still needs to learn such things as subject-verb agreement, and some irregular past tense verbs. Can take appropriate turns in a conversation. Gives and receives information. Communicates well with family, friends, or strangers.

Cognitive Skills		Self-Help Skills	Social Skills
Plays with words (creates own rhyming words; says or makes up words having similar sounds). Points to and names 4 to 6 colors. Matches pictures of familiar objects (for example, shoe, sock, foot; apple, orange, banana). Draws a person with 2 to 6 recognizable parts, such as head, arms, legs. Can name or match drawn parts to own body. Draws, names, and describes recognizable picture. Rote counts to 5, imitating adults.	Knows own street and town. Has more extended attention span. Learns through observing and listening to adults as well as through exploration. Is easily distracted. Has increased understanding of concepts of function, time, part/whole relationships. Function or use of objects may be stated in addition to names of objects Time concepts are expanding. The child can talk about yesterday or last week (a long time ago), about today, and about what will happen tomorrow.	Cuts easy foods with a knife (for example, hamburger patty, tomato slice). Laces shoes.	Plays and interacts with other children. Dramatic play is closer to reality, with attention paid to detail, time, and space. Plays dress-up. Shows interest in exploring sex differences.
Retells story from picture book with reasonable accuracy. Names some letters and numerals. Rote counts to 10. Sorts objects by single characteristics (for example, by color, shape, or size. Is beginning to use accurately time concepts of **tomorrow and yesterday.** Uses classroom tools (such as scissors and paints) meaningfully and purposefully.	Begins to relate clock time to daily schedule. Attention span increases noticeably. Learns through adult instruction. When interested, can ignore distractions. Concepts of function increase as well as understanding of why things happen. Time concepts are expanding into an understanding of the future in terms of major events (for example, **Christmas will come after two weekends**).	Dresses self completely. Ties bow. Brushes teeth unassisted. Crosses street safely.	Chooses own friend(s). Plays simple table games. Plays competitive games. Engages with other children in cooperative play involving group decisions, role assignments, fair play.

☆ U.S. GOVERNMENT PRINTING OFFICE : 1978 O—270-712

Table A

DIAGNOSTIC CRITERIA FOR REPORTING HANDICAPPED CHILDREN IN HEAD START

All children reported in the following categories* must have been diagnosed by the appropriate professionals who work with children with these conditions and have certification and/or licensure to make these diagnoses.

Blindness - A child shall be reported as blind when any one of the following exists: (a) a child is sightless or who has such limited vision that he/she must rely on hearing and touch as his/her chief means of learning; (b) a determination of legal blindness in the state of residence has been made; (c) central acuity does not exceed 20/200 in the better eye, with correcting lenses, or whose visual acuity is greater than 20/200, but is accompanied by a limitation in the field of vision such that the widest diameter of the visual field subtends an angle of no greater than 20 degrees.

Visual Impairment [Handicap] - A child shall be reported as visually impaired if central acuity, with corrective lenses, does not exceed 27/70 in either eye, but who is not blind; or whose visual acuity is greater than 20/70, but is accompanied by a limitation in the field of vision such that the widest diameter of visual field subtends an angle of no greater than 140 degrees or who suffers any other loss of visual function that will restrict learning processes, e.g., faulty muscular action. Not to be included in this category are persons whose vision with eyeglasses is normal or nearly so.

Deafness - A child shall be reported as deaf when any one of the following exists: (a) his/her hearing is extremely defective so as to be essentially nonfunctional for the ordinary purposes of life; (b) hearing loss is greater than 92 decibels (ANSI 1969) in the better ear; (c) legal determination of deafness in the state of residence.

Hearing Impairment [Handicap] -A child shall be reported as hearing impaired when any one of the following exists: (a)

* **Multiple handicaps:** Children will be reported as having multiple handicaps when in addition to their primary or most disabling handicap one or more other handicapping conditions are present.

From: The Status of Handicapped Children in Head Start Programs, February 1980.

the child has slightly to severely defective hearing, as determined by his/her ability to use residual hearing in daily life, sometimes with the use of a hearing aid; (b) hearing loss from 26-92 decibels (ANSI 1969) in the better ear.

Physical Handicap [Orthopedic Handicap] - A child shall be reported as crippled or with an orthopedic handicap who has a condition which prohibits or impedes normal development of gross or fine motor abilities. Such functioning is impaired as a result of conditions associated with congenital anomalies, accidents, or diseases; these conditions include, for example, spina bifida, loss of or deformed limbs, burns with cause contractures, cerebral palsy.

Speech Impairment [Communication Disorder] - A child shall be reported as speech impaired with such identifiable disorders as receptive and/or expressive language impairment, stuttering, chronic voice disorders, and serious articulation problems affecting social, emotional, and/or educational achievement; and speech and language disorders accompanying conditions of hearing loss, cleft palate, cerebral palsy, mental retardation, emotional disturbance, multiple handicapping condition, and other sensory and health impairments. This category excludes conditions of a transitional nature consequent to the early developmental processes of the child.

Health Impairment - These impairments refer to illness of a chronic nature or with prolonged convalescence including, but not limited to, epilepsy, hemophilia, severe asthma, severe cardiac conditions, severe allergies, blood disorders (e.g., sickle cell disease, hemophilia, leukemia), diabetes, or neurological disorders.

Mental Retardation - A child shall be considered mentally retarded who, during the early developmental period, exhibits significant subaverage intellectual functioning accompanied by impairment in adaptive behavior. In any determination of intellectual functioning using standardized tests that lack adequate norms for all racial/ethnic groups at the preschool age, adequate consideration should be given to cultural influences as well as age and developmental level (i.e., finding of a low I.Q. is *never by itself sufficient* to make the diagnosis of mental retardation).

Serious Emotional Disturbance - A child shall be considered seriously emotionally disturbed who is identified by professionally qualified personnel (psychologist or psychiatrist) as requiring special services. This definition would include but not be limited to the following conditions: dangerously aggressive towards others, self-destructive, severely withdrawn and non-communicative, hyperactive to the extent that it affects adaptive behavior, severely anxious, depressed or phobic, psychotic or autistic.

Specific Learning Disabilities - Children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental disadvantage. For preschool children, *precursor functions* to understanding and using language spoken or written, and computational or reasoning abilities are included. (Professionals considered qualified to make this diagnosis are physicians and psychologists with evidence of special training in the diagnosis of learning disabilities and at least Master's degree level special educators with evidence of special training in the diagnosis of learning disabilities.)

USING AN OBSERVATIONAL CHECKLIST

The checklist of behaviors that follows for each of eight disability groupings can alert you to undiagnosed problems in a child and help you to know when to refer that child for professional evaluation. For example, in the case of a hearing impairment, there are certain aspects of the child's medical history that are important to note on your checklist, in addition to observable behaviors. The child's records or the child's parents can help answer the "medical history" questions. The checklist can then be completed from your observations.

If a child displays two or more of the behaviors listed, watch him or her more closely and in a variety of situations. Look carefully for other listed behaviors. You may also want to ask parents or other staff if they have observed any of the behaviors on the checklist. Two or more checks in a "Yes" or "Often or always" column may indicate a child has a serious problem. With the possibility of a serious problem, you should consult someone in your program about referring the child for professional evaluation.

From the child's point of view, referral is better than non-referral; that is, if you think a handicap might account for the behavior you have observed, it is best to have the child professionally evaluated. If you later learn the child does not have a handicap, no harm has been done. If, on the other hand, a handicapped child is not diagnosed, the child's special needs will not be met. Referral is also preferred over non-referral for children who already have been diagnosed, as children can be incorrectly evaluated. If you suspect a problem, therefore, do discuss the referral with an appropriate colleague.

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* Adapted from the series on Mainstreaming Preschoolers for the Head Start Bureau, by the staff of CRC Education and Human Development, Inc.

	MOTOR PROBLEMS	YES	NO
1.	The child has apparent weakness of muscles, trembling or shaking.	☐	☐
2.	The child complains of pain after physical exercise.	☐	☐
3.	The child does not alternate feet going up or down stairs.	☐	☐
4.	The child is generally awkward or clumsy or has balance problems, stumbles or falls easily.	☐	☐
5.	The child has very negative reaction to even a light, unexpected touch.	☐	☐
6.	The child has difficulty in holding and using pencils or scissors.	☐	☐
7.	The child runs or jumps with unusual difficulty.	☐	☐
8.	The child fears or avoids activities that require movement.	☐	☐
9.	The child has twitching or jerking movements. He/she seems to have better control of the leg and arm on one side than on the other.	☐	☐
10.	The child walks on tiptoes much of the time.	☐	☐
11.	The child walks stiff-legged.	☐	☐

HEALTH PROBLEMS	**YES**	**NO**
1. The child is frequently absent or truant from school (one day per week or more).	☐	☐
2. The child has bruises or cuts around face, arms, more than one incident or unusually severe.	☐	☐
3. The child has colds, sore throat, runny nose, or cough; persistent for several weeks or recurring weekly for several weeks.	☐	☐
4. The child is often tired, lacks energy; either severe day to day change, or persisting over two weeks.	☐	☐
5. The child has frequent or extreme hunger or thirst, or need to use the toilet.	☐	☐
6. The child complains of aches and pains; persisting over 2 or 3 weeks.	☐	☐
7. The child is extremely restless; can't stay still.	☐	☐
8 The child is unusually small and thin for age, or very obese.	☐	☐
9. The child is unusually slow, listless or lethargic, dreamy and unresponsive.	☐	☐

	EMOTIONAL BEHAVIOR PROBLEMS	YES	NO
1.	The child has sudden change in behavior, normally quiet student becomes a behavior problem; sudden withdrawal or failure in subjects in which performance was normal.	☐	☐
2.	The child engages in inappropriate laughing or crying; strange or bizzare talk.	☐	☐
3.	The child masturbates openly or is sexually aggressive (touching or grabbing other students, not part of normal horseplay).	☐	☐
4.	The child uses obscene language OUT OF CONTEXT (not as "cursing" or "swearing").	☐	☐
5.	The child tries to hurt self (cuts, burns, strikes self).	☐	☐
6.	The child is unstable and unpredictable. Cries easily with little cause, or loses temper explosively (pattern persistent over one month).	☐	☐
7.	The child is very easily upset; has tantrums or cries often.	☐	☐
8.	The child has extreme difficulty paying attention or concentrating.	☐	☐
9.	The child seems unaware of what goes on around him/her; seems to "live in his or her own world".	☐	☐
10.	The child seems fearful, anxious or tense much of the time.	☐	☐
11.	The child appears listless and uninterested.	☐	☐
12.	The child appears very sad over a period of several days.	☐	☐
13.	The child can't sit still; is extremely restless or hyperactive.	☐	☐
14.	The child has to be reprimanded or controlled by teacher because of behavior in class several times each day, over a period of weeks.	☐	☐
15.	The child can't tolerate normal frustrations like waiting in line to go to lunch.	☐	☐

MENTAL RETARDATION

Information Coming from the Environment

	Often or always	Rarely or never
The child doesn't understand directions, reacts slowly to them, or waits to see what the other children are doing first.	☐	☐
The child seems confused and doesn't do what other children are doing along with them.	☐	☐
The child doesn't know what to do with materials and toys, or uses them for the wrong purposes.	☐	☐
Loud sounds disturb the child.	☐	☐
A lot of unorganized moving around in the classroom confuses the child.	☐	☐
The child has trouble noticing fine details.	☐	☐
The child doesn't answer to his or her name.	☐	☐
The child can't carry out a one-step direction.	☐	☐
The child can't concentrate on one thing for very long, and is easily distracted.	☐	☐
The child doesn't show interest in classroom surroundings.	☐	☐

Processing the Information

	Often or always	Rarely or never
The child has trouble remembering what he or she has seen or heard, or what has happened.	☐	☐
The child can't match colors and shapes.	☐	☐
The child can't sort colors and shapes.	☐	☐
The child can't answer simple questions (such as "What's your name?") or gives answers that make no sense.	☐	☐
The child doesn't know things that other children in the class know.	☐	☐
The child does things in the wrong order (such as drying the pan before it has been washed).	☐	☐
The child can't predict dangerous consequences of actions before he or she does them.	☐	☐
The child can't hear small differences in words (such as boy/toy, Fred/red).	☐	☐
The child can't retell a simple story.	☐	☐
The child has trouble following two or more directions in the right order.	☐	☐
The child doesn't understand common environmental sounds (for example, can't tell you "a car" upon hearing the beep of a car horn).	☐	☐
The child doesn't remember the classroom routine.	☐	☐
The child forgets what he or she is doing in the middle of it.	☐	☐
The child has trouble inventing stories and actions in pretend play.	☐	☐
The child doesn't understand basic concepts such as relationships, time, space, and quantity as well as other children do.	☐	☐

MENTAL RETARDATION

Using the Information

	Often or always	Rarely or never
Verbal Responses: Talking		
The child doesn't talk at all.	☐	☐
You can't understand the child's speech.	☐	☐
The child can't communicate using words and gestures, either alone or together.	☐	☐
The child can't name or describe familiar objects.	☐	☐
Motor Responses: Moving the Body		
The child trembles or shakes.	☐	☐
The child falls down or bumps into things a lot.	☐	☐
The child walks unevenly, or limps.	☐	☐
The child has poor eye-hand coordination (for example, knocks things over a lot).	☐	☐
The child can't pull simple clothing on or off.	☐	☐
The child has trouble using toys such as blocks and puzzles.	☐	☐
The child can't copy simple forms, such as a line, circle, square.	☐	☐

The Child's Behavior in the Classroom

	Often or always	Rarely or never
The child resists change and variety in activities by crying, throwing tantrums, or refusing to participate.	☐	☐
The child cannot make choices about what to do or select activities independently.	☐	☐
The child imitates the games of other children rather than inventing his or her own games.	☐	☐
The child withdraws from participating in most or all of the activities.	☐	☐
The child is constantly disrupting the class.	☐	☐

SPEECH AND LANGUAGE IMPAIRMENTS

Articulation

	Often or Always	Rarely or Never
After 24 months, the child uses mostly vowel sounds (oo, ah, ee) and gestures when talking.	☐	☐
After 36 months, the child leaves out the first sound in many words (says "at" for "cat" or "es" for "yes").	☐	☐
After 42 months, friends, neighbors, and teachers cannot understand most of what the child says.	☐	☐
At any age, the child seems embarrassed or disturbed about his or her speech.	☐	☐
At any age, speech sounds are more than a year late in developing. (See pg. 31 for the developmental sequence and average ages of speech sound production.)	☐	☐

Voice

	Often or Always	Rarely or Never
The child's voice is so soft that he or she can barely be heard.	☐	☐
The child's voice is extremely loud.	☐	☐
The child's pitch is inappropriate (too high or too low) for the child's sex and age.	☐	☐
The child's voice sounds hoarse, strained, or unusual in some way.	☐	☐
The child's speech is denasal (sounds as if he or she has a cold or sinus condition).	☐	☐
The child's speech is hypernasal (sounds seem to be spoken through the nose rather than through the mouth).	☐	☐

Rhythm

The child has noticeable difficulty and seems to struggle trying to say words or sounds.	☐	☐
The child is aware of this difficulty.	☐	☐
There is an abnormal amount of hesitation, repetition of sounds ("cuh-cuh-can") or words ("but-but-but"), and/or prolongation of sounds ("ssssomething") or words ("mmmmeeee") in the child's speech, and the child seems aware of it.	☐	☐

SPEECH AND LANGUAGE IMPAIRMENTS

Reception

	Often or Always	Rarely or Never
After 24 months, the child cannot point to common objects that are named.	☐	☐
After 24 months, the child cannot understand simple one-part directions, such as "Bring me the ball."	☐	☐
After 36 months, the child repeats questions rather than answering them. For example, when asked, "What did you do yesterday?" the child responds, "Do yesterday."	☐	☐
After 48 months, the child cannot follow two-part directions, such as "Put the book away and get a chair."	☐	☐
After 48 months, the child is unable to respond, even with appropriate gestures, to a slightly complex question such as "What do you do when you're thirsty?"	☐	☐
After 48 months, the child seems confused when asked a question or when the class is given instructions. The child waits to see what the other children are doing when directions are given.	☐	☐

Expression

	Often or Always	Rarely or Never
After 24 months, the child has not yet started talking.	☐	☐
After 36 months, the child cannot put words together to make simple sentences such as "Give me more juice."	☐	☐
After 48 months, the child cannot tell a recent series of events.	☐	☐
After 48 months, there are unusual word confusions or substitutions of words when the child talks. For example, the child may say "I want a crayon" for "I want a pencil," or "Give me the stove thing" for "Give me a pot."	☐	☐
After 60 months, most of the child's grammar and sentence structure seems noticeably faulty, and is unlike the communication pattern used in the child's home.	☐	☐

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* Many of the items in this checklist were obtained from **Getting a HEAD START on Speech and Language Problems** by Susan Hansen. Copyright 1974 Meyer Children's Rehabilitation Institute, 444 South 44 Street, Omaha, Nebraska 68131.

LEARNING DISABILITIES

Child's Name ______________________________ *Birth Date* __________

Date ____________ *Teacher's Name* ______________________________

Communicative Skills

	Yes	*No*	*Sometimes*
1. Does the child use at least two- and three-word phrases to ask for what he or she wants? (For example, "more juice" or "more juice please.")	☐	☐	☐
2. Does the child use complete sentences to tell you what has happened? (For example, "My doggie ran away" versus "doggie gone.")	☐	☐	☐
*3. When the child is asked to describe something, does he or she use at least two sentences to talk about it?	☐	☐	☐
4. Does the child ask questions? (For example, "Where is Juan?")	☐	☐	☐
5. Does the child seem to have difficulty following directions?	☐	☐	☐
6. Does the child respond to questions with an appropriate answer?	☐	☐	☐
7. Does the child seem to talk too softly or too loudly?	☐	☐	☐
8. Are you able to understand the child?	☐	☐	☐
9. Does the child have difficulty paying attention to group activities for more than five minutes at a time?	☐	☐	☐

* *Question applies if child is four years or older.*

Motor Skills

	Yes	No	Sometimes
10. Does the child stumble often, or appear awkward when he or she moves?	☐	☐	☐
11. Does the child seem afraid of or unable to use stairs, climbing equipment, or tricycles?	☐	☐	☐
12. When the child walks or runs, does one side of his or her body seem to move differently than the other side? For instance, does the child seem to have better control of the leg and arm on one side than on the other?	☐	☐	☐
13. Can the child hop on one foot?	☐	☒	☐
*14. Is the child capable of dressing him- or herself except for tying shoes?	☐	☒	☐
15. Does the child hold a pencil or a crayon appropriately with the thumb, index, and middle fingers?	☐	☒	☐
16. Does the child continually switch a crayon from one hand to the other when coloring?	☐	☐	☐
17. Do the child's hands appear clumsy or shaky when he or she is using them?	☒	☐	☐
18. When the child is coloring with a crayon, does the hand that he or she is *not* using appear tense? (For example, clenched into a fist.)	☒	☐	☐
19. Can the child color inside a circumscribed area with any accuracy?	☐	☒	☐
20. Can the child cut with a pair of scissors?	☐	☒	☐

* *Question applies if child is four years or older.*

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Social Skills

	Yes	No	Sometimes
21. Does the child engage in at least two disruptive behaviors a day? (For example, tantrums, fighting, screaming.)	☐	☐	☐
22. Does the child appear withdrawn from the outside world? (For example, fiddling with pieces of string, staring into space, rocking his or her body, banging his or her head, talking to him- or herself.)	☐	☐	☐
23. Does the child appear extremely shy in group activities? (For example, does the child avoid volunteering answers or answering direct questions, even when you think he or she knows the answers?)	☐	☐	☐
24. Does the child play alone and seldom talk to the other children?	☐	☐	☐
25. Does the child spend most of the time trying to get attention from the adults?	☐	☐	☐
26. Does the child have toileting problems (wet or soiled) at least once a week?	☐	☐	☐

Vision or Hearing Skills

	Yes	No	Sometimes
27. Do the child's eye movements appear jerky or uncoordinated?	☐	☐	☐
28. Does the child seem to have difficulty seeing objects?	☐	☐	☐
. . .tilt his or her head to look at things?	☐	☐	☐
. . .hold objects close to his or her eyes?	☐	☐	☐
. . .squint?	☐	☐	☐
. . .show sensitivity to bright lights?	☐	☐	☐
. . .have uncontrolled eye-rolling?	☐	☐	☐
. . .complain that his or her eyes hurt?	☐	☐	☐
. . .bump into things constantly?	☐	☐	☐
29. Does the child appear awkward in tasks requiring eye-hand coordination? (For example, pegs, puzzles, coloring.)	☐	☐	☐
30. Does the child seem to have difficulty hearing?	☐	☐	☐
. . .consistently favor one ear by turning the same side of his or her head in the direction of the sound?	☐	☐	☐
. . .ignore, confuse, or not follow directions?	☐	☐	☐
. . .rub or pull on his or her ear frequently, or complain of earache?	☐	☐	☐
. . .complain of head noises or dizziness?	☐	☐	☐
. . .have a high, low, or monotonous tone of voice?	☐	☐	☐
. . .respond to your voice when he or she is not looking at you?	☐	☐	☐
. . .ask "what?" excessively?	☐	☐	☐
. . .have speech that is very difficult for you to understand?	☐	☐	☐

General Health

	Yes	No	Sometimes
31. Does the child seem to have an excessive number of colds?	☐	☐	☐
32. Does the child have frequent absences because of illness?	☐	☐	☐
33. Do the child's eyes water?	☐	☐	☐
34. Does the child have a discharge from his or her eyes?	☐	☐	☐
. . .his or her ears?	☐	☐	☐
35. Does the child have periods of unusual movements (such as rapid eye blinking) or "blank spells" that seem to appear and disappear without relationship to the social situation?	☐	☐	☐
36. Does the child have hives or rashes?	☐	☐	☐
Does the child wheeze?	☐	☐	☐
37. Does the child have a persistent cough?	☐	☐	☐
38. Is the child excessively thirsty?	☐	☐	☐
. . .ravenously hungry?	☐	☐	☐
39. Have you noticed any of the following conditions?			
. . .constant fatigue	☐	☐	☐
. . .irritability	☐	☐	☐
. . .restlessness	☐	☐	☐
. . .tenseness	☐	☐	☐
. . .feverish cheeks or forehead.	☐	☐	☐
40. Is the child overweight?	☐	☐	☐
41. Is the child physically or mentally sluggish?	☐	☐	☐
42. Has the child lost weight without being on a diet?	☐	☐	☐

VISUAL IMPAIRMENT

Behavior

	Yes	No
Rubs eyes excessively.	☐	☐
Shuts or covers one eye, tilts head, or thrusts head forward.	☐	☐
Has difficulty in work that requires close use of the eyes (such as putting puzzle parts together, or matching identical shapes).	☐	☐
Blinks more than usual, or is irritable when doing close work.	☐	☐
Holds objects close to eyes.	☐	☐
Is unable to see distant things clearly.	☐	☐
Squints eyelids together or frowns.	☐	☐

Appearance

Has crossed eyes.	☐	☐
Eyelids are red-rimmed, crusty, or swollen.	☐	☐
Eyes are inflamed or watery.	☐	☐
Has recurring styes (small inflamed swellings on the rim of the eyelid).	☐	☐

Complaints

Eyes itch, burn, or feel scratchy.	☐	☐
Cannot see well.	☐	☐
Has dizziness, headaches, or nausea following close eye work.	☐	☐
Has blurred or double vision.	☐	☐

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* Adapted from "Signs of Possible Eye Trouble in Children." Available from National Society for the Prevention of Blindness, New York, New York.

HEARING IMPAIRMENT

Speech

	Yes	No
Does the child frequently say "Huh?" or "What?" or show other signs of not understanding what has been said?	☐	☐
Does the child use very little speech?	☐	☐
Does the child have difficulty controlling how loudly or softly he or she speaks?	☐	☐
Does the child have trouble putting words together in the right order?	☐	☐
Does the child's voice seem too high-pitched, too low-pitched, or too nasal?	☐	☐
Is the child's speech full of words and sentences that cannot be understood or recognized?	☐	☐
Does the child have poor articulation?	☐	☐

Other Behavior

	Yes	No
Does the child have a short attention span?	☐	☐
Does the child seem frequently restless?	☐	☐
Does the child breathe with his or her mouth open?	☐	☐
Is the child seldom the first one to do what the teacher has asked the group to do?	☐	☐
Is the child easily frustrated or distracted in a group?	☐	☐
Does the child tend to play in the quietest group?	☐	☐
Does the child tend to play alone more than the other children do?	☐	☐
Does the child seem unaware of social conventions? For example, does the child:	☐	☐
• never say automatically "thank you," "excuse me," or "sorry"?	☐	☐
• generally tap or grab another person instead of calling his or her name?	☐	☐
• not become quiet in quiet areas or activities (church, story corner, naptime)?	☐	☐
• not ask permission to leave the room, go to the bathroom, get a drink?	☐	☐
• appear unaware of disturbing others with noises?	☐	☐

HEARING IMPAIRMENT

Medical History

	Yes	No
Is there a history of earaches or ear infections in the child's records?	☐	☐
Does the child complain of earaches, ringing, or buzzing in the ears?	☐	☐
Does the child have allergies or what appear to be chronic colds?	☐	☐
Has the child had a disease (mumps, measles) accompanied by a high fever?	☐	☐
Do parents say that they have wondered if the child has a hearing loss?	☐	☐

Hearing

	Yes	No
Does the child fail to respond to loud, unusual, or unexpected sounds?	☐	☐
Does the child fail to respond to communication that excites the other children? (For example, "Who wants ice cream?")	☐	☐
Does the child frequently fail to understand or respond to instructions or greetings when he or she doesn't see the speaker?	☐	☐
Does the child seem to watch other children rather than listen to the teacher in order to learn what to do next?	☐	☐
Does the child have difficulty finding the source of a sound?	☐	☐
Does the child constantly turn the television, radio, or record player up louder?	☐	☐
Does the child's attention wander or does the child look around the room while the teacher is talking or reading a story?	☐	☐

ERIC

ERIC Clearinghouse on Handicapped
and Gifted Children

FACT
SHEET

LEARNING DISABILITIES

What is a learning disability?

The term *learning disability* has been used to describe a variety of problems in acquiring, storing, and/or retrieving information.

Students with learning disabilities receive inaccurate information through their senses and/or have trouble processing that information. Like static on the radio or a bad TV picture, the information becomes garbled as it travels from the eyes, ears, or skin to the brain.

This inaccurate sensory information, sometimes called perceptual problems, leads to difficulty in academic work. The student might have difficulty reading, writing, speaking, or listening. These skills either have not been learned, have been learned after heroic work, or have been learned poorly.

The most commonly used definition is taken from The Education for All Handicapped Children Act of 1975, Public Law 94-142. It states:

> The term "children with specific learning disabilities" means those children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia. Such term does not include children who have learning problems which are primarily the result of visual, hearing or motor handicaps, of mental retardation, of emotional disturbance, or environmental, cultural or economic disadvantage.

What are the problems associated with various learning disabilities?

Many handicaps come under the term *learning disabilities*. Following are those that most hinder academic performance.

Visual perceptual problems. Difficulty taking information in through the sense of sight and/or processing that information.

Visual figure-ground problems. Difficulty seeing a specific image within a competing background; for example, seeing the teacher's face when he or she stands in front of a blackboard with writing on it or picking out one line of print from other lines on a page. People who have this problem cannot see things that others can see. One line of print on the page appears to be missing.

Visual sequencing problems. Difficulty seeing things in the correct order, for instance, seeing letters reversed or seeing two knobs reversed on a machine. The person who has this problem actually sees the word incorrectly; he or she sees *was* instead of *saw*.

Visual discrimination problems. Difficulty seeing the difference between two similar objects, such as the letters *v* and *u* or *e* and *c*; between two similar chemical symbols; or between two types of leaves.

Auditory perceptual problems. Difficulty taking information in through the sense of hearing and/or processing that information. People with this problem frequently hear inaccurately. A sequencing or discrimination error can totally change the meaning of a message. For example, one might hear, "The assignment is due in May," rather than "The assignment is due today." People with auditory handicaps frequently do not hear unaccented syllables. They may hear "formed" instead of "performed," or "seven" instead of "seventy." Some auditory preceptual handicaps are:

- *Auditory figure-ground problems*. Difficulty hearing a sound over background noise, for instance, hearing the professor lecture when an air conditioner is humming in the room, hearing one bird chirp while other birds and insects are singing, or hearing someone talk at a party when music is playing.
- *Auditory sequencing problems*. Difficulty hearing sounds in the correct order, for instance, hearing "nine-four" instead of "four-nine," hearing "law" instead of "wall," or hearing music garbled because the notes are perceived out of order.
- *Auditory discrimination problems*. Difficulty telling the difference between similar sounds such as "th" and "f" and "m" or "n," hearing "seventeen" instead of "seventy," or hearing an angry rather than a joking tone of voice.

Motor problems. Difficulty moving one's body efficiently to achieve a certain goal. Following are some motor problems:

- *Perceptual motor problems.* Difficulty performing a task requiring coordination, because of inaccurate information received through the senses. This may result in clumsiness, difficulty in participating in simple sports, and awkward or stiff movements.
- *Visual motor problems.* Difficulty seeing something and then doing it, such as copying something off a blackboard or learning a dance step by watching the teacher.
- *Auditory motor problems.* Difficulty hearing something and then doing it, such as following verbal directions on a test or taking notes in a lecture.

Intersensory problems. Difficulty using two senses at once or associating two senses, for instance, not realizing that the letter *D* that is seen is the same as the sound "D."

Handicaps Classified by Academic Difficulty

Dyslexia—Inability to read.
Dysgraphia—Inability to write.
Dyscalculia—Inability to do math.

National Organizations and Associations

Association for Children and Adults with Learning Disabilities (ACLD), 4156 Library Road, Pittsburgh PA 15234. Phone: (412) 341-1515.
Description: ACLD is a nonprofit organization whose purpose is to advance the education and general welfare of children of normal or potentially normal intelligence who have learning disabilities.
Periodicals: *ACLD Newsbriefs* (newsletter), six issues/year, included with membership of $10/year or available by subscription for $4.50.

The Orton Society, 8415 Bellona Lane, Towson MD 21204. Phone: (301) 296-0232.
Description: The Orton Society is an educational and scientific association founded in 1949. Members are concerned with the diagnosis and treatment of specific language disability or developmental dyslexia.
Periodicals: *Perspectives on Dyslexia* (newsletter), *Bulletin of the Orton Society* (annual journal), included with membership of $25/year, or available separately for $7.00.

The Council for Exceptional Children's Division for Children with Learning Disabilities (DCLD), 1920 Association Drive, Reston VA 22091. Phone: (703) 620-3660; Toll Free: (800) 336-3728.
Description: The purpose of DCLD is to promote the education and general welfare of children with specific learning disabilities through improving teacher preparation programs, improving local special education programs, resolving the research issues, and coordinating activities with other CEC divisions and with professional organizations outside the Council structure. Membership: CEC $25/year, DCLD $8/year.
Periodicals: *Learning Disability Quarterly* is issued to the membership four times a year. Content includes educational articles with an applied emphasis that focuses on learning disabilities. *LDQ* is available by subscription to nonmembers ($12.50 per year domestic; $16.00 per year PUAS, libraries, and other countries). Single copy price is $3.50.

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1920 Association Drive, Reston, Virginia 22091
1980

INFORMATION FROM . . . .

CLOSER LOOK

A Project of the Parents' Campaign for Handicapped Children and Youth

Box 1492
Washington, D.C. 20013

GETTING TO KNOW EACH OTHER

A reading list to help you learn more about children and youth who have handicaps

A little nursery school child, born without arms, was queried by a worried older child, "What happened to you?" The young boy answered — simply, openly, honestly — "I came that way." As we read and learn, and our knowledge about handicapped people increases, let's have all our feelings and communications open, and direct and honest. We all should be able to say, "I came that way." That's the way it is — let's move on from here. There's life and love and meaning in the world for all of us.

This reading list is for you. Parents, professionals, handicapped young people — all of us need to know more about what really makes us more alike than different. These books are not technical. They're written in response to the need to know more about handicapping conditions. Some are by lay people who want to share their experiences, and others are by professionals who have gathered helpful information.

Share these books with libraries. Ask your librarians to set up a shelf so that everyone interested in the rights, the needs and the humanness of handicapped people can find the books quickly.

Maybe you are planning to volunteer your services to a group of handicapped children, or to an individual child, or to a classroom. As handicapped children are "mainstreamed," all kids benefit. With knowledge and understanding, attitudes change.

Groups can read and benefit. If you are a member of a Parent-Teacher Association or a church study group, or an organization of parents of handicapped children or a Lions Club or a Kiwanis Club — use these books. The groups are all good forums in which to learn and share knowledge of handicapped individuals — our fellow citizens.

Employers, workers in industry and people who are trying to open opportunities for handicapped job-seekers need to learn more about how to break down age-old barriers to employment of the handicapped. These books will help efforts to change traditional work patterns.

(over, please)

Some of the books can best be read together -- parents and child, teachers and parents, teachers and children. As you read, questions come up. Understanding develops as you discuss and explore.

It should be remembered no book is the final word . . . we are all listening and learning. There is fresh enjoyable reading here, too, as the fine honing of pain brings a bright burst of humor.

Read and learn, share, discuss, explore, disagree with and enjoy. We hope that you will interact with these readings and that your interaction will be a catalyst for more caring -- and for more action.

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BOOKS FOR YOUNGER READERS

ABOUT HANDICAPS

By Sara Bonnet Stein, Walker and Company, 720 Fifth Avenue, New York, New York 10019 (1974) 44 pp.

Designed for children and grown-ups to use together and separately, and deals honestly with a little boy's feelings about a disabled playmate. It has easy-to-read type and fine photographs to help a child sort out the truth from imaginings he may have about handicapped people he meets.

ANNA'S SILENT WORLD

Text and photographs by Bernard Wolf, J. B. Lippincott Company, East Washington Square, Philadelphia, Pennsylvania 19105 (1977) 48 pp.

Anna was born deaf. Although her hearing loss is profound, Anna has learned to speak and to understand people around her. Therapy enables her to go to school with children who have normal hearing.

CHALLENGE OF A HANDICAP

By Caroline Clark Myers and Walter B. Barbe, Highlights for Children, 2300 West Fifth Avenue, P.O. Box 269, Columbus, Ohio 43216 (1977) 33 pp.

Illustrated with watercolor sketches and photographs, this booklet is a collection of stories and articles about persons with handicaps. It is designed to give young people some idea of what it is like to be disabled.

CONNIE'S NEW EYES

Text and photographs by Bernard Wolf, J. B. Lippincott Company, East Washington Square, Philadelphia, Pennsylvania 19105 (1976) 95 pp.

Connie David has been blind since birth and is about to begin her first full time teaching job. She is also about to become the owner of a guide dog. Sensitive photographs and text show how a Seeing Eye puppy is raised and trained. For all ages.

DON'T FEEL SORRY FOR PAUL

Text and photographs by Bernard Wolf, J. B. Lippincott Company, East Washington Square, Philadelphia, Pennsylvania 19105 (1975) 94 pp.

About a physically handicapped seven year old with a real zest for life. Excellent photographs -- along with written explanations of how he uses his prosthetic devices. Paul's everyday life includes school, parties, and horse shows. Any age could learn from this.

FEELING FREE

By Mary Beth Sullivan, Alan J. Brightman and Joseph Blatt, Addison-Wesley, Children's Books, General Book Division, Reading, Massachusetts 01867 (1979) 188 pp.

Introduces young people to their disabled peers by using short stories, photographs, games, drawings and activities.

LISA AND HER SOUNDLESS WORLD

By Edna S. Levine, illustrated by Gloria Kamen, Human Sciences Press, Inc., 72 Fifth Avenue, New York, New York 10011 (1974) 30 pp.

A lovely story about Lisa and the ways she learns to communicate with others -- by lip-reading, hearing aid, sign language, and finger-spelling. For the young reader.

MORE TIME TO GROW

By Sharon Hya Grollman, Beacon Press, 25 Beacon Street, Boston, Massachusetts 02108 (1977) 98 pp.

A good short story that will help every parent and teacher explain to children the words "mental retardation." Also includes questions to think about, activities for children, a guide for parents and teachers, and recommended resources on retardation.

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BOOKS FOR OLDER READERS

THE ABC'S OF HANGING ON

By Betty Oliver, Claitor's Publishing Division, 3165 South Acadian at I-10, P.O. Box 3333, Baton Rouge, Louisiana 70821 (1976) 118 pp.

Betty Oliver, a parent of a disturbed child, has written a helpful, practical book for other parents who are faced with the need for a fresh approach to a difficult task.

THE ACORN PEOPLE

By Ron Jones, Abingdon Press, 201 Eighth Avenue South, Nashville, Tennessee 37202 (1976) 75 pp.

A warm, sometimes funny, account of counselors and a group of handicapped kids and their adventures at summer camp.

AUTISTIC CHILDREN: A GUIDE FOR PARENTS AND PROFESSIONALS

By Lorna Wing, M.D., D.P.M., Brunner/Mazel, Inc., 19 Union Square West, New York, New York 10003 (1972) 157 pp.

Informative and down-to-earth. Dr. Wing describes autistic children and their special problems of communication and behavior. She gives suggestions about education and management of these special children.

THE DISABLED AND THEIR PARENTS: A COUNSELLING CHALLENGE

By Leo Buscaglia, Charles B. Slack, Inc., 6900 Grove Road, Thorofare, New Jersey 08086 (1975) 393 pp.

A strong, well-documented appeal to teachers, physicians, psychologists -- all people in the helping professions. Focuses on the deep, largely unmet need of disabled people and their families for help in dealing with their feelings as they cope realistically with disabilities. An outstanding contribution.

DOES SHE KNOW SHE'S THERE?

By Nicola Schaefer, Doubleday and Company, 501 Franklin Avenue, Garden City, New York, New York 11530 (1978) 235 pp.

In this book, Mrs. Schaefer tells the story of her daughter, who is a severely-involved, nonverbal, retarded cerebral palsied teenager whose presence in their family is a happy fact of life. While she acknowledges the difficulties of her daughter's daily care, she expresses the positive things that have come from having her at home. Her battles for better short and long term care arrangements for severely handicapped people are outlined; although she is Canadian, her experiences with this frustrating process will sound familiar to parents here in the United States, also.

ELIZABETH

By Sharon Ulrich, University of Michigan Press, 615 East University, Ann Arbor, Michigan 48106 (1972) 122 pp.

This is a beautifully written biography by Elizabeth's mother. The discovery of her daughter's blindness at two months enabled her to get early infant education. Commentaries by two experts who worked with Elizabeth offer helpful information.

THE EXCEPTIONAL PARENT

Exceptional Parent Magazine, P. O. Box 4944, Manchester, New Hampshire 03108
One-year subscription (6 issues)

A magazine which deals with the kinds of problems faced by all parents of disabled children. In addition to articles filled with practical information, it presents a lively forum for an exchange of parents' ideas and experiences.

GROWING UP HANDICAPPED

By Evelyn West Ayrault, The Seabury Press, 815 Second Avenue, New York, New York 10017 (1978) 216 pp.

Helpful advice and suggestions for bringing up a child who has a disability are offered in this book. Behavior, discipline, problems of adolescence and adulthood are among the subjects discussed.

IS MY BABY ALL RIGHT?

By Virginia Apgar, M.D., M.P.H., and Joan Beck, Pocket Books, Division of Simon and Schuster, Inc., 1230 Avenue of the Americas, New York, New York 10020 (1972) 542 pp. (paperback)

This is an informative, readable discussion of the causes, treatment and/or prevention of many common birth defects.

JOEY (also published under the title: TONGUE TIED)

By Joseph John Deacon, Charles Scribner's Sons, 597 Fifth Avenue, New York, New York 10017 (1974) 92 pp.

A heart-warming story of incredible courage and creative teamwork of four severely handicapped men who wrote the story of Joey Deacon's life. Joey Deacon has cerebral palsy which affects all four limbs and his speech. His autobiography brings to us the vital message of the precious quality of life of each individual.

LEARNING DISABILITIES, A FAMILY AFFAIR

By Betty B. Osman, Random House, Inc., 201 East 50th Street, New York, New York 10022 (1979) 224 pp.

Offers advice to a learning disabled child's parents on counteracting classroom failure, distinguishing among types of learning disabilities, keeping academic learning disabilities from snowballing into behavior problems, and coping with the imposition of a learning disabled child's needs on family members. It contains information about diagnosis, what particular remedial experts do, and suggestions about techniques of dealing with homework assignments.

LIKE NORMAL PEOPLE

By Robert Meyer, McGraw-Hill Book Company, 1221 Avenue of the Americas, New York, New York 10020 (1978) 196 pp.

Well-written and unsentimental, the book describes the growing up years of the author's retarded brother. Good description of what was happening in the field of mental retardation during that period. You get a sense of how narrowly the author's brother escaped being "thrown away."

LIVING WITH OUR HYPERACTIVE CHILDREN

By Marvin L. Bittinger, Editor, BPS Books, Inc., Two Continents Publishing Group, Ltd., 30 East 42nd Street, New York, New York 10017 (1977) 199 pp.

A useful and interesting book written by parents of hyperactive children. The child in each family is different and the progress made, difficulties encountered and management used, both medical and educational, are clearly spelled out.

SCHIZOPHRENIA

By Kayla F. Bernheim and Richard R. J. Lewine, W. W. Norton and Company, Inc., 500 Fifth Avenue, New York, New York 10036 (1979) 256 pp.

The authors present a balanced overview of the many aspects of schizophrenia in non-technical readable language. The book is current, well researched and informative for families and professionals. It is sympathetic and helpful to families who are faced with the task of being the primary care giver to their child or spouse in the absence of adequate community support systems.

SEIZURES, EPILEPSY AND YOUR CHILD

By Jorge C. Lagos, M.D., Harper & Row, 10 East 53rd Street, New York, New York 10022 (1974) 238 pp.

This book is written in a question and answer format in an informative direct style. Medical, social, psychological and educational aspects of epilepsy are covered. Charts listing treatment, drugs, milestones of psychomotor development, and familial risk factors are included.

THE SIEGE

By Clara Claiborne Park, Little, Brown and Company, 34 Beacon Street, Boston, Massachusetts 02106 (1967) 280 pp. NOTE: This book is out of print, but is available in some public libraries.

Offers a parent's view of living with an autistic child. Mrs. Park describes in great detail not only what she did to help her daughter, but how she patiently tailored her teaching to the child's readiness.

SO YOUR CHILD HAS CEREBRAL PALSY

By Gil F. Joel, University of New Mexico Press, University of New Mexico, Albuquerque, New Mexico 87131 (1975) 53 pp. (paperback)

Written by an adult born with cerebral palsy who has counseled families of the physically handicapped. It suggests how parents can be most effective in helping their child develop a positive self-image and in their own ability to cope.

THE SPECIAL CHILD HANDBOOK

By Joan McNamara and Bernard McNamara, Hawthorn Books, Inc., 260 Madison Avenue, New York, New York 10016 (1977) 320 pp.

Written by parents of five adopted handicapped children, the authors provide practical information on finding schools, programs, support and financial assistance. Also has a directory of state agencies and organizations to contact for additional help.

SPECIAL PEOPLE

By Shirley Cohen, Prentice-Hall, Inc., Englewood Cliffs, New Jersey 07632 (1977) 177 pp.

Closely examines some of the prejudices toward handicapped persons. The book also gives real insight into how these attitudes affect people.

TO RACE THE WIND

By Harold Krents, Bantam Books, Inc., 666 Fifth Avenue, New York, New York 10019 (1972) 282 pp. (paperback)

The autobiography of an irrepressible young man who insists that he make his own way in the mainstream, not in a segregated blind world. His humor, love of life, unquenchable demand for independence all contribute richly to self-realization and success.

YOU ARE NOT ALONE

By Clara Claiborne Park with Leon N. Shapiro, M.D., Little, Brown and Company, 34 Beacon Street, Boston, Massachusetts 02106 (1976) 496 pp.
Consumer's Union Edition, Consumer Reports, A087 Consumer's Union, Orangeburg, New York 10962 (1976) 496 pp.

A comprehensive guide for people who want reliable information about emotional problems, mental illness, and how to get professional help. It is straightforward and unbiased toward any one method of treatment. The reading lists and running summaries in the margins make it a useful source of information. This book has been long awaited and is much needed.

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Developmental Screening of Preschool Children: A Critical Review of Inventories Used in Health and Educational Programs

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ABSTRACT. Five developmental screening inventories, currently popular in health and educational programs, are compared on relevant technical and practical criteria. All five have limitations because their norms are based on small samples of children who are often not representative of the children later screened. Until carefully conducted longitudinal studies of normal children of different racial, socioeconomic, and educational backgrounds are available, these inventories cannot be used for prediction of future potential. However, when administered by a properly trained person, each of these procedures can be used as a narrative description—if not a numerical score—a profile for planning the health and education of the preschool child. *Pediatrics*, 53:362, 1974, CHILD DEVELOPMENT, SCREENING, DENVER DEVELOPMENTAL, HEAD START, INVENTORIES, PRESCHOOL, SCHOOL READINESS, THORPE DEVELOPMENTAL.

This paper is intended to aid pediatricians and psychologists in comprehending the similarities and differences between commonly used inventories of child development. Although applications and interpretations are discussed, the administration of these tests or surveys requires special training, with close study of directions, for which the references in the bibliography should be consulted. After completing such training, the pediatrician should be able to administer these inventories himself or delegate the procedure to trained nurses, educators, psychologists or paraprofessionals.

WHY DEVELOPMENTAL SCREENING?

All children develop psychomotor functions that follow progressive sequences along four separate, distinctive patterns.[1-7]

I. *Gross motor abilities* emphasize the integration of the central nervous and musculo-skeletal systems.

II. *Communication skills* include comprehension, expression, hearing and speech.

III. *Fine motor skills* require eye–hand coordination.

IV. *Personal–social behavior* relates to self-care and interaction with others.

Because of genetic and environmental factors, children may exhibit individual variations in developmental rates in each of these categories.

Prior to 1966, developmental screening was the responsibility of highly skilled, trained psychologists and pediatricians. It was also the technical task least delegated by pediatricians to allied health workers.[8,9] Since the late 1960's health components (staff and services) have been incorporated into publicly funded preschool programs, allowing low income families to have new sources of care.[10,11] Title XIX, the early periodic screening diagnosis and treatment program,[12,13] requires developmental screening as part of the health screening for children who are welfare recipients. In addition, middle class families are requesting similar health services. They often seek developmental screening from private medical care prior to enrolling their children in private or public preschool programs.

During the last decade, developmental screening procedures have been designed by pediatricians, psychologists, and educators in an attempt to provide tools that could be used by paraprofessionals and professionals alike to meet the increased need for developmental screening. Although a comprehensive review of infant and preschool tests ap-

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peared in 1965,[14] the five developmental screening tests or inventories now most frequently used had not then been developed.

This review will, therefore, compare the practical and technical aspects of (1) the Denver Developmental Screening Test (DDST)[15-20]; (2) the Head Start Developmental Screening Test and Behavior Rating Scale (HSDS)[21-26]; (3) the Cooperative Preschool Inventory (CPI)[27-30]; (4) the School Readiness Survey (SRS)[31-35]; (5) the Thorpe Developmental Inventory (TDI).[36-41]

Tables I, II, III, IV and V present a comparative summary of the items in the five developmental inventories by the four categories of skills assessed. This includes all the items of the HSDS, CPI, SRS, and TDI. It includes all the items for ages 3 to 6 years that could potentially be asked on the DDST.

PRACTICAL ASPECTS

As indicated above, all five inventories are intended for the assessment of a child's developmental status *prior* to intervention and at periodic intervals *after* specific educational and health programs have been introduced. The greatest potential use of these screening methods is in a setting of continued care of the individual child. Therefore, unlike the familiar milestones of development, they are not designed to yield age equivalents. Nor are horizontally parallel items in Table I intended to indicate expectation of similar age at accomplishment.

TABLE I

COMPARISON OF ITEM CONTENT OF FIVE DEVELOPMENTAL SCREENING INVENTORIES*

I. GROSS MOTOR ABILITIES

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
1. Walk forward	Recorded only at ages 11-12 mo Can be passed by report† (norms, 1-1.3 yr)	Not asked	"Jump" is only gross motor skill asked	No observational items Parents answer yes or no to whether their child can 1. walk backwards 2. stand on one foot 5-10 sec 3. alternate feet walking downstairs 4. walk a straight line	All items are observed Separate scoring for child's response to spoken directions or following visual examples (>2-3 yr)
2. Walk backwards	Can be passed by report (norms, 1.3-1.10)				(>2-3 yr)
3. Forward heel-toe	No specified line on floor (3.6-5)	Norms 6 mo later than DDST (4-5.6)			Masking tape line on floor (3-5 yr)
4. Backward heel-toe	(4.9-6+)	(5.6-6+)			(3.6-5.6 yr)
5. Balance right foot left foot 10 sec	Examiner is required to observe skill of *only* one foot (4.6-6 yr)	Skill observed on one foot only Norms 6 mo earlier than DDST (4-5.6)			Skill of each foot recorded (3.6-5)
6. Hop right foot left foot	Skill of only one foot required Norms 1 yr earlier than DDST (3.6-5)	Skill of only one foot required Norms 1 yr earlier than DDST (3-4 yr)			Skill of each foot recorded (3.9-5)
7. Skip alternating feet	Not asked	Not asked	Not asked	Not asked	(5-6 yr)

* Abbreviations—DDST, Denver Developmental Screening Test (copyrighted); HSDS, Head Start Developmental Screening Test (not copyrighted); CPI, Cooperative Preschool Inventory (copyrighted); SRS, School Readiness Survey (copyrighted); and TDI, Thorpe Developmental Inventory (copyrighted).

Each inventory is administered by one adult interacting with one child. None of these inventories is performed by a series of adults doing just one skill area.

Norms (years and or years and months in parentheses) are indicated when 50% to 90% of healthy children have the given developmental skills based on the standardized performance of children reported for each inventory. This age-range norming is available only for the DDST, HSDS and the TDI. CPI gives a child one point for each correct response for a total score of 64 possible. SRS gives point scores which are interpreted as "ready for school," "border-line ready," or "needs to develop."

† Report items can be passed by parent history report and are not scored differently from observed data. The examiner is not required to observe these items.

TABLE II A

Comparison of Item Content of Five Developmental Screening Inventories*
II. Communication Skills: Self-Identity and Sentence Use

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
1. What is your name?	May be passed by report† (2.6–3.9)	May be passed by report† Norm is 1 yr later than DDST (3–4.11)	Child must know meanings of "first" and "last" to answer questions	Tell full name	Exact response recorded (2.6–4)
2. Are you a boy or a girl?	Not asked	Not asked	Not asked	Not asked	(2.6–4)
3. What do you do when you are —hungry? —sleepy? —cold?	Child's exact response is *not* recorded Examiner *interprets* and gives a pass if 2 of the 3 questions are answered with logical response (3–4.3)	Same item as DDST. Norm is 6 mo later (3.6–4.8)	Exact response is *not* recorded "Pass" means a "logical" answer was given to —Who do you go to if you are sick? —Where do you find a boat? —Where do you buy gas? —When is breakfast? —Where do you find a lion? —What does mother do? —What does a dentist do? A teacher?	Not asked	Exact response is recorded and scored for appropriateness, length of phrase, or sentence, and use of pronouns —hungry (2.6–5) —sleepy (3.6–5) —cold (3.6–5)
4. What do you do when you want to cross the big street and many cars are coming?	Not asked	Not asked	Not asked	Parent history: question on child's understanding of how to cross a residential street safely	Asked and exact response is recorded (4–5.6)
5. What do you do when you lose a toy?	Not asked	Not asked	Not asked	Not asked	Asked and child's exact response is recorded (4–5.6)

* See Table I footnote.

† See Table I footnote.

TABLE II B

Comparison of Item Content of Five Developmental Screening Inventories*
II. Communication Skills: Comprehension and Expression

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
1. Point to —red —yellow —blue —green	"Pass" indicates child recognizes any 3 of the 4 colors May be passed by report† (3–4.9)	Same item as DDST Pass by report† Norm is 1 yr later (4.4–5.6)	Child recognizes red, yellow & blue objects Child uses yellow, purple & orange crayons on record form	Color recognition is not asked	Response to each color is separate recorded: red & yellow, (3.6–5 yr) blue & green, (4–5 yr)
2. Name —red —yellow —blue —green	Not asked	Not asked	Name black & red	Name 7 colors: red, yellow, blue, pink, orange, green & purple	Name red & yellow (4–5.6) Name blue & green (4.6–5.6)

TABLE II B (*Continued*)

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
3. Prepositions —under —on —behind —in front of	"Pass" if child follows any 3 of 4 directions correctly (3–4.6)	Same item as DDST Norms 1 yr later (3.6–5.6)	Prepositions are part of questions measuring 3 concepts at the same time	Not asked	Under and on, (2.6–3) Behind & in front of (3.6–5)
4. Points to body parts	Child is required to identify only 1 body part to pass May be passed by report† Asked only at ages 14–24 mo (1.6–2 yr)	Child identifies 1 body part to pass Pass by report† ([illegible]–3.6)	Child shows adult his shoulder & heel Child names finger, knee & elbow	Not asked	(2.6–3) Child identifies five parts
5. Right/left identification	Not asked	Not asked	Not asked	Not asked	(5.6–6+)
6. Count 4 objects 7 objects 2 objects	No numerical or quantitative concepts are screened	Not asked	How many eyes? Count to 5 How many wheels on a bike, car & trike? How many corners on a paper? How many toes?	Child points & counts: 3, 6, 9, 5, 7, 4 and 24 boxes on a page of the record book	Four objects (4–5 yr) Seven objects (4.6–6) Two objects (3.6–4.6)
7. Repeat 2 digits— three four	Not asked No items screen short-term verbal memory	Not asked	Not asked	Four digits only	2 (2.6–4) 3 (3.6–5) 4 (4–5.6)
8. Recognition vocabulary and articulation	Children ages 14–28 mo are asked to name 1 of 5 pictures presented together Pictures are of cat, bird, horse, dog & man These are not drawn to relative size Info on articulation is not obtained	No items screen recognition vocabulary or articulation of speech sounds	No picture vocabulary or speech sounds are screened	Child names 20 small pictures presented in rows of 5 (1 in) line drawings. Child points to 12 pictures named by adult	Child names 18 pictures in Spanish or English Each picture is presented individually Articulation of 17 sounds is recorded
9. Name plurals	May be passed by report† (2.3–3.3)	May be passed by report† (2.6–3.8)	Not asked	Not asked	(3–4.6)
10. Describe opposites	"Pass" if child answers 2 of 3 questions correctly (3–5.6)	Same administration as DDST Norms are 6 mo later (4.6–6+)	Not asked	Six asked	Six asked (3–5 yr)
11. Description of objects pictures words	Child defines 6 out of 9 words Not "culture free" (5–6 yr)	Not asked with objects or pictures	Child asked to tell which way water falls, how a record goes, which way a ferris wheel turns	Not asked	Three objects, two pictures, five words Separate norms for each item

* See Table I footnote.
† See Table I footnote.

TABLE III

Comparison of Item Content of Five Developmental Screening Inventories*
III. Fine Motor Skills

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
1. Handedness using crayons; content of spontaneous drawing	Not recorded	Not recorded	Not recorded	No fine motor skills observed	Recorded Drawings are reviewed and scored
2. Draw a circle	Child is asked to copy unnamed object (2.6–3.6)	Child is asked to copy unnamed object (2.6–3.8)	Child is asked to copy unnamed object	Parent history: "Can your child draw or copy a plus, box and a ball"?	Recorded separately if child follows spoken directions or imitates example (2.6–4)
Draw a cross	Child is asked to copy unnamed object (3.6–4.6)	(3.6–4.6)	Not asked	Not asked	(3.6–4.6)
Draw a box	Imitate (4–5.6) Copy (4.6–6)	Imitate (4.6–6) Copy (5–6)	Copy		(4–5.6)
3. Draw a picture of child like himself	Three parts (4–5) Six parts (4.9–6)	Three parts (4–5.6) Six parts (5.2–6+)	Not asked	Not asked	Age 3—2 parts 3.6—3 parts 4—4 parts 4.6—5 parts 5—6 parts 5.6—7 parts
4. Completing outline of incomplete man	Not asked	Not asked	Not asked	Not asked	Drawings reviewed and quantitative scoring done

* See Table I footnote.

All items on the CPI, SRS, and TDI are administered. For the DDST and HSDS, the examiner varies the number of items asked, depending on the child's age and success or failure in doing the inventory. Scoring of the DDST depends on the number of items passed or failed in relation to the response of the normative sample. A failure on the DDST is the inability of the child to do a series of items at an age when 90% of the normative sample correctly performs these items. The normative sample contains relatively few low-income or minority children. The scoring of the HSDS is related to norms of 900 Head Start children who do colors and prepositions one year later, tandem walk six months later, and balance and hop six months earlier than the DDST normative sample. The CPI and SRS convert items correct to a number score, with interpretation dependent on the child's age. The TDI records the child's response in descriptive terms. The TDI record is then coded for computer analysis of responses by items and qualitative scores. Raw scores and equivalent scores have been calculated for each 6-month age range, from ages 3 years to 6 years, and are based on over 3,000 California children from migrant, Head Start, parent participating, and private preschool programs. The TDI score correlates developmental data with health data.

TECHNICAL ASPECTS

The potential user of the developmental screening inventories (whether administered by himself or another) should be aware of the following limitations.

The *sample* of children employed in standardizing each of the inventories may not be representative of the populations to which these procedures are applied. This is evident particularly for the DDST and SRS. For example, the Menninger Foundation reported in a recent review: "From our clinical use of DDST we have had some reason to question the circumscribed geographical selection of the sample and applicability of norms in screening children from lower socioeconomic groups, especially in the language area."[25] Only three of the developmental inventories (the HSDS, CPI and TDI) have included Head Start children in their standardization samples. Only the TDI has a recording form in Spanish and norms on children of migrant farm workers.

The *reliability* of the inventories is based on tester–observer and test–retest studies from small samples and heterogenous age ranges that were tested at widely different intervals (DDST)[19] or on yet unpublished studies (TDI). No evidence of tester–observer or test–retest reliability has, as yet, been published for either the HSDS or CPI. A common problem in reliability is illustrated by a Philadelphia study of 104 children from low-income families (65% Puerto Rican and 35% Negro)[20]; four trained first-year medical students achieved a reliability between examiners of 62% to 79% (DDST) with variability in judgment based on examiner's uncertainty in recording child's nonresponse as "failure" or "refusal." It was noted that history from parent was NOT equivalent to observation.

The *validity* of all five inventories is based on age differentiation, or on correlations with *concurrently* administered other tests or ratings by pediatricians, parents or teachers. Some of the results of validity studies of the most publicized test, the DDST, are not as encouraging as one would hope for.[19] For example, a *concurrent validity* study of the DDST by Frankenburg *et al.* mislabeled normal children over the age 30 months as abnormal. Forty-two percent of the children scoring in the normal range on the Revised Yale Developmental Schedule (RYSD) were called abnormal on the DDST. Both tests were given by professionally trained examiners."[21] In Hawaii Head Start projects, trained aides screened 208 children with the DDST. The correlation between the aides' DDST scores and psychologists' Stanford-Binet IQs for the same children was only .30.[22] A Philadephia study[21] of 373 Negro children from low-income families showed abnormal ratings based on a consistent pattern of *refusals, not incorrect responses.* Motor, language and fine motor skills were markedly delayed compared to original DDST norms.

Predictive validity is lacking for all five inventories. This would require follow-up studies showing the relationship of the results of the inventory to certain relevant criteria which are independently ascertained. These could include grade retention, special class placement, school adjustment and general academic success several years later.

INTERPERSONAL ASPECTS OF DEVELOPMENTAL APPRAISAL

A wide range of adults, from indigenous nonprofessionals to professionals with varying child development backgrounds, are given new responsibilities in developmental screening.[17] Thus, the skills which were previously delegated to highly trained child psychologists and pediatricians are being practiced by less trained individuals. This may create problems in interpretation of the inventories.

A screening instrument, even the simplest, is only as good as the sensitivity of its user to the behavior of young children. The examiner must understand the importance of nonverbal clues from facial expressions, eye movements, and gestures. The rapport established between the adult and child, as well as the examiner style, will influence the child's performance.

The examiner should be capable of spontaneous and varied delivery so a relaxed and inviting atmosphere can be maintained. The approach to a child aged 3 to 6 years is different from the approach to infants or toddlers or to older children. Instructions to the child must be brief and clear to

TABLE IV

COMPARISON OF ITEM CONTENT OF FIVE DEVELOPMENTAL SCREENING INVENTORIES*

IV PERSONAL SOCIAL ADAPTIVE SKILLS

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
1 Open and close snappers 2 Button and unbutton 1", 1½" 3 Zip up and down 4 Open and close belt buckle 5 Lace shoes 6 Tie shoe lace bows 7 Drink from cup without spilling	Pass by report† (3-4.3) No standard method to observe self-skills	Pass by report†	None asked	History of button and zip skills	Each item observed with standardized button book Norms for each item

* See Table I footnote.
† See Table I footnote.

TABLE V

COMPARISON OF ITEM CONTENT OF FIVE DEVELOPMENTAL SCREENING INVENTORIES*
V. HEALTH DATA

Category of Skill	*DDST*	*HSDS*	*CPI*	*SRS*	*TDI*
1. Health history 2. Parent data 3. Vision and hearing screening	Not asked	Not asked	Not asked	Not asked	Integral part of recording form *Essential for interpreting developmental data*

* See Table I footnote.

adapt to his short attention span and easy distractibility. The examiner must be alert to signs of fatigue, drowsiness, fear and inattentiveness, and appropriately adjust or postpone the screening. A preschool child is particularly sensitive to interpersonal aspects of this encounter. It takes time and patience to overcome shyness, distractibility and negativeness which are normal behavioral characteristics of this age range. Thus, the examiner style is best developed by a thorough training program.

TRAINING FOR PROFESSIONALS AND PARAPROFESSIONALS IN DEVELOPMENTAL SCREENING

Of the five developmental inventories, only the DDST and the TDI have specific training programs aimed at different levels of involved health and educational staff.

Information on the DDST was initially read by physicians in the pediatric literature.[18] Kits and manuals became available at no cost from Mead Johnson. Medical students, interns, residents, and pediatricians in private practice soon had access to the manual, kit and forms. Preparation for use has consisted in many instances of reading the manual and "trying it." Thus, the professional using his own background, knowledge and skill has adapted these "Gesell" type items to his own clinical needs. There are probably almost as many versions of performing the DDST as there are physicians using it.

The American Academy of Pediatrics, in its *Standards of Child Health Care,*[19] suggests the DDST or items adapted from it as a screening tool and includes a copy of the form and some instructions for administration. However, it omits guidelines for minimum numbers of items to be performed, the criteria for interpretation, or the need for training. All of these are essential in decreasing the over-referral of normal children, especially by paraprofessionals.

Nurses affiliated with nursing schools, state and junior colleges, health departments and regional centers have introduced their version of DDST to public health and school nurses after attending 40-hour workshops in Denver. A review of a sample of such workshops in California and interviews with faculty and participants reveals the following: the participants in the workshops are *not* required to perform the inventory on any specific number of children in each age range. There is no standardized, supervised practice requirement for inter-examiner reliability for these workshops. It is assumed that self-motivation will guide the proper use of DDST. This practice is in contrast to the recommendations by Frankenburg and associates who have reported on training-indigenous health aides.[17] Their suggestions include tutorial approach for one or two trainees and uniform prepared format for ten or more trainees. The latter would include written material and films for consistent presentation, role playing and supervised practice experience. The authors note with caution: "Proficiency of test administration or observation decreases when the aides no longer think their work is being checked. Therefore, to assure a high level of screening accuracy, it is important to make periodic checks of screening results."[16]

The same cautionary statements should be made in the use of the other four screening inventories which are being used with increasing frequency, predominantly in preschool programs.

The Head Start Developmental Screening Test (HSDS)[20] was distributed by Head Start since 1968 without manuals, kits or standardized training programs. In 1970 to 1971 it was used in fewer than 6% of the sample of Head Start projects surveyed by national monitoring teams.[10] The staff did not know how to perform it, what to do with the data, or how to share it with parents or health professionals. Pediatric consultants were unaware that the norms in this modification of the DDST were different. On the HSDS a child is considered normal, rather than delayed, if he passes items on color and on prepositions a year later than is acceptable on the DDST.

The Cooperative Preschool Inventory[27, 28] is commercially distributed by Cooperative Tests and Services. As prepost gains have been used as criteria of effectiveness of preschool instruction in California,[32] teachers are credited for "gains in points." Thus, the lower the pretest and the larger the gain, the more credit is given to the teacher's instructional effort. No studies have been conducted of reliability between examiners performing this inventory in these preschool programs.[30, 31]

The School Readiness Survey is commercially distributed by the Consulting Psychological Press with directions in the form serving as the only required preparation prior to use.[34]

The Thorpe Developmental Inventory has a minimum of ten hours of training programs for nurses and educators. A consistent format of slides, films and videotapes, role-playing and supervised practice supplement the instructional manual.[38-41] The inventory can be performed and recorded in Spanish for children who are not bilingual. The record contains descriptive as well as interpretive data. Health data and behavioral data are integral parts of the recording form.

SUMMARY

Five developmental screening inventories currently popular in health and educational programs are here compared on relevant technical and practical criteria. All five have limitations because their norms are not universally applicable and because information is as yet limited on reliability and validity. Until carefully conducted longitudinal studies are available, the predictive validity of each inventory is unknown.

A tool is only as good as its user. Reliable performance is directly related to the preparation, training and supervision of the examiners. Not until these aspects are standardized can it be accepted that a developmental appraisal is made adequately.

Developmental screening is an essential component of health and educational evaluation of preschool children. The adult who performs this screening may be a pediatrician, or a nurse, or an educator, or a paraprofessional. The most important factors are the skills the adult has in relating to children and the knowledge an adult has in proper administration and recording of the screening tool. Interpretation and referral should be accomplished by skilled pediatricians, psychologists, and educators.

Developmental screening inventories are human instruments and designed for human purposes. By themselves they treat no patients, educate no children, solve no social problems. But in the hands of skilled professional or paraprofessional workers they can help in all these undertakings.[46]

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Professional Competence
and the
Assessment of Exceptional Children*

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Abstract

This paper presents the argument that serious problems exist with regard to the competence of professionals involved in the assessment of exceptional children. The argument is presented through citation of opinions and perceptions related to problems in professional performance, review of research on professionals' test scoring skill, and discussion of research and documentation related to the placement of children in special education. Recommendations for improving the competence and performance of professionals are also given. These include suggestions for research aimed at identifying specific areas of training need for particular groups of professionals, inservice efforts to address areas of documented training need, and consideration of a performance-based certification system to assure adequate levels of professional competence. Only through such comprehensive evaluation, training and certification efforts can quality assessment services be provided and maintained.

Professional Competence
and the
Assessment of Exceptional Children

Recently, a great deal of concern has been expressed regarding the adequacy with which children are assessed for identification of handicap, diagnostic classification, educational placement, and instructional programming. Much of this concern has focused upon the quality of assessment tools presently in use (e.g., Salvia & Ysseldyke, 1978; Wallace & Larsen, 1978). Concern has also been expressed, though far less adamantly, over professionals' tendency to bias judgments as a result of pupil characteristics such as sex, race, physical appearance, and diagnostic label (e.g., Foster & Salvia, 1977; Gillung & Rucker, 1977). This paper, while recognizing that concern for the quality of tests and the problem of bias is legitimate, raises a third concern: that serious problems exist with regard to the competence of professionals involved in the educational and psychological assessment of children. The paper will discuss this concern by (a) citing opinions and perceptions related to problems in professional performance, (b) reviewing research on professionals' test scoring skill, and (c) discussing research and documentation related to the placement of children in special education. Suggestions for improvement of professional performance in assessment will also be presented.

Professional Competence and Assessment: Opinions and Perceptions

Numerous opinions and perceptions regarding the competencies of those involved in the assessment of children have recently been reported in the professional literature. Ysseldyke (1978a, 1978b) believes that many school personnel administer and interpret tests without the training to do so. He believes these personnel fail to consider the technical limitations of the devices they use, fail to account for the reliability of difference scores when conducting profile analyses, and are generally unaware of the nature of the standardization samples for tests they use daily.

Garry McDaniels, director of the Office of Special Education's Division of Assistance to States, notes that professional competence in the selection and administration of tests for placing children into programs for the learning disabled is an issue of concern (McDaniels, 1979). McDaniels also notes that the two issues most frequently encountered in regard to implementation of PL 94-142 relate to measurement practice and personnel training as opposed to improvements in the technology of measurement.

A perception of frequent misuse of the Illinois Test of Psycholinguistic Abilities (Kirk, McCarthy, & Kirk, 1968), a widely used special education assessment tool, is reported by Kirk and Kirk (1978). Kirk and Kirk state that many examiners fail to follow procedures given in the test manual and hence inappropriately use the test.

"Overzealous and incorrect interpretations of test results" are seen as partial cause for widespread criticism of intelligence testing, by Salvia and Ysseldyke (1978, p. 457). These authors believe that such incorrect interpretations are evidenced to a greater degree in every other kind of standardized testing of school aged children.

MacMillan and Meyers (1977) see signs of inadequate preparation in some assessment personnel. They state that one means of complying with the nondiscriminatory testing provision of Public Law 94-142 is through issuance of guidelines for certification, and enactment of procedural safeguards designed to combat abuses to children resulting from irresponsible administration, scoring, and interpretation of tests.

Bransford (1974), too, believes that many training programs do not adequately prepare professionals for the assessment of children. In particular, such programs are deficient in imparting techniques for establishing rapport, and in teaching analysis and interpretation of assessment data, especially in regard to the evaluation of minority children.

The presence of inadequately prepared professionals on assessment teams is also discussed by Meyers, Sundstrom, and Yoshida (1974). These authors feel this presence has resulted from the recency of legally specified standards of preparation enabling the current employment of hundreds of professionals who have "grandfathered in" on old requirements, lack of provision for updating skills, and lack of emphasis in preparation on assisting the teacher plan an educational program for the child.

Outright charges of "inappropriate and unprofessional behavior" are made by Kirp and Kirp (1976, p. 85) against those responsible for evaluation of children for special class placement. As documentation for their charges, these authors cite instances of children being classified as mentally retarded solely because of poor performance on an intelligence test given in a language they did not speak, and of classification made on the basis of only a short form of an IQ test.

In sum, it is evident from the opinions and perceptions cited that concern exists as to the knowledge and competence of at least some of those involved in the assessment of children. To what extent is this concern justified? An answer to this question is suggested by the results of research and other relevant documentation.

Professional Competence and Assessment:
Research on Test Scoring

With any measuring technique, it is essential that those involved in the measuring process show a high level of agreement among themselves in reporting or judging equivalent behaviors. If an acceptable agreement level is not achieved, then either the procedure's scoring system is ambiguous or otherwise faulty, or the group of examiners is in need of further training in the system's use.

One index of the extent to which examiners agree among themselves in scoring is provided by the standard deviation of scores given to the same test protocol by a group of examiners. The greater the standard deviation of these scores, the greater is the disagreement within the group. The standard deviation, then, provides a measure of the degree of "error" in test scores to be expected because of rater disagreement.

Objective tests are so called because they are constructed to eliminate to the maximum extent possible, problems of rater disagreement. For this reason, the standard error of measurement for an objective test, as normally calculated, is meant to reflect sources of error other than that due to examiner variability. In studying the degree to which the assumption of objectivity is valid for a particular test, comparison of a measure of examiner variability in scoring to the standard error of measurement is sometimes undertaken. If examiner variability is sizable in relation to the standard error of measurement, examiner variability should be taken into account as an additional error source in test interpretation. In addition, attempts should be made to improve the test's scoring system or enhance examiner scoring ability, or both.

Oakland, Lee and Axelrad (1975) asked psychologists to score three actual WISC protocols taken from the files of one of the investigators. Each of the three protocols represented a child of a different ability level (i.e., below average, average, above average). Data were analyzed from the returned protocols of 94 of 400 psychologists randomly selected from directories of the APA's Divisions of Educational and School Psychology and from the National Association of School Psychologists. While the authors interpret their results as reflecting a generally high level of agreement among examiners, their data do not fully support this conclusion. The standard deviation of the Verbal IQ's derived by examiners for the above average child exceeds the standard error of measurement for the test. In addition, for four of the eight remaining IQ scores the standard deviations very nearly equal the standard errors of measurement.

Oakland et. al's data can be interpreted then, to suggest that interrater disagreement is a source of error that should be considered in WISC interpretation. Exploration of a number of other studies will assist in both confirming this suggestion, and in sorting out the causes for examiner variability.

Miller, Chansky, and Gredler (1970) investigated rater agreement on WISC protocols by examining responses of 32 psychologists in training. Thirty-one of the subjects had completed course work in administration and scoring of the WISC, with the remaining subject being concurrently enrolled in the course. All trainees were asked to score the same bogus protocol which had been prepared by the investigators. The standard deviations for all three IQ's (i.e., Verbal, Performance, and Full Scale) exceeded the average standard errors of measurement for their respective scales. Examination of the individual subtest data showed that the greatest amount of variability was attached to those subtests for which the WISC manual did not give comprehensive scoring criteria (i.e., Comprehension, Vocabulary, Information, and Similarities). This suggests that one cause of examiner variability was the inadequacy of the Wechsler scoring system. However, one other cause of examiner variability was identified.

Miller et. al. counted the total number of mechanical scoring errors for the group finding it to be 68, or 2.12 per examiner. Calculation errors, crediting items after cutoff, crediting incorrect responses, conversion errors, failure to credit correct responses, and failure to credit non-administered test items below basal level, were detected. The net result of examiner errors and inadequate scoring criteria was a single WISC protocol with Full Scale IQ ranging from 76 to 93. Unfortunately, Miller et. al. provide no suggestion as to the relative contributions of these two causes of examiner variability.

Miller et. al's. study can be criticized on the grounds that it used trainees with no real backlog of experience in the administration and scoring of tests. Perhaps it was this thought that motivated these researchers to attempt replication of the study with practicing psychologists.

Miller and Chansky (1972) randomly selected 200 professional psychologists from the APA Directory of Members, receiving 64 responses. Analysis of data showed the standard deviation for Verbal IQ to exceed the average standard error of measurement for the scale, and the ratio of standard deviation to standard error for Performance and Full Scale IQ's to be .48 and .80 respectively. A mean of 2.37 mechanical errors per examiner was found, a figure remarkably consistent with the mean number of errors per trainee in the earlier study. In addition, Full Scale IQ was determined to range from 78 to 95 for the same protocol. The authors note that this range of scores would qualify the examinee for class placements varying from those for the educable mentally retarded, through slow learner, to regular placement. It should be noted that the sources of error normally present in objective tests (e.g., changes in the individual from time to time, variation in response to the test at a particular moment in time, changes in the specific sample of tasks), were controlled by Miller and Chansky so that the range of IQ scores observed was solely the result of rater disagreement.

Some concerns need to be expressed regarding the methodology employed by Oakland et. al. (1975) and Miller and Chansky (1972). First, in each study the proportion of subjects who failed to return the mailed protocols was substantial (i.e., 76% and 68% respectively). There is no way of knowing if failure to respond was in some way related to test scoring skill. Oakland et. al., however, state that a number of protocols were returned unscored with accompanying notes indicating that the respondents judged themselves unqualified to score the tests (presumably because they did not perform such testing as part of their vocational responsibilities). In addition, the systematic relationship between tendency to respond and examiner scoring skill, if it exists, may well be such that those who failed to respond also tended to be among the less adept users of the test. If this were the case, the results of Oakland et. al., and Miller and Chansky might show an overestimate of rater agreement and examiner scoring ability.

A second methodological concern is related to the extent to which protocols were conscientiously scored by respondents. It could be argued that protocols might be more accurately scored in the actual assessment situation where the types of decisions made about children demand scoring accuracy. Some guidance as to the degree of scoring accuracy present in a context more closely resembling the actual assessment situation is gained from a study conducted by Warren and Brown (1973).

Warren and Brown compiled a checklist of scoring errors from professional experience, review of the WISC and Stanford-Binet manuals, and pilot research. One hundred-twenty WISC, and an equal number of

Binet protocols from the actual administrations of the tests given by forty students were analyzed for errors. Protocols were taken from those administered during the beginning and end of training. Errors detected included failure to follow prescribed manual procedures, failure to establish proper basal and ceiling levels, conversion errors in use of tables, mistakes in addition and subtraction, and faulty computation of chronological age. A total of 1,939 errors was observed, for an average of eight errors per protocol. Thirty-seven percent of the protocols contained errors that changed IQ, with changes varying from 1 to 16 points on the WISC and 1 to 13 points on the Binet. Finally, error frequency did not show significant decrease as a result of training.

The result of Warren and Brown is sobering in its suggestion that scoring error exists in situations resembling actual assessment. The study's second finding, that training may not have a significant effect upon scoring ability, needs to be tempered by the results of other studies (e.g., Boehm, Duker, Haesloop, & White, 1974; Foster, Boeck, & Reese, 1976) that have found training to be effective. Resolution of the contradictory findings of these studies might best be attempted through comparison of the training programs used. Unfortunately, no description of treatment is given by Warren and Brown, making such comparison impossible.

In conclusion, research on individual intelligence test scoring can be taken to suggest support for the following:

1. Interrater variation represents a source of error that closely approximates in magnitude other sources of error usually found in objective tests.

2. Some portion of this interrater variability is due to examiner mechanical scoring error.

3. The frequency of mechanical scoring error is about the same for students who have recently completed training in test administration as for practicing professionals.

4. The magnitude of mechanical error noted in non-assessment situations is at least as great in situations closely resembling actual assessment.

5. Training may have a substantial effect upon scoring proficiency.

This research then, tends to support the concern expressed earlier that problems exist in the way professionals are using tests. Further documentation to support this concern, particularly with reference to special class placement, will now be presented.

Professional Competence and Assessment:

Research and Documentation Related to Special Class Placement

The professional involved in the assessment of children plays a central role in the provision of services for children with special needs. This is so because individual evaluation is required to confirm the existence of a special need and to justify the provision of special services (U.S. Office of Education, 1977). Errors in the assessment process resulting in misclassification can lead to denial of services to those in need, or at the other extreme, the possible stigmatization of children who are not exceptional. The assessment of children for the purpose of special placement is therefore an undertaking requiring a high level of professional skill.

Investigations into the relationship between assesment competence and special class placement have unfortunately been few in number and limited in scope. Review of those studies that have been conducted and discussion of documentation provided by litigative action may provide an initial impression of the role of assessment competence in erroneous placement.

A survey of 39 Child Service Demonstration Centers serving 26 states was conducted by Thurlow and Ysseldyke (1979) to discover the types of procedures used in special education assessment and the purposes for which specific procedures are employed. The Centers were funded by the Bureau of Education for the Handicapped to develop exemplary practices in the education of learning disabled children and to serve as models for the way services should be provided to this group. Professionals typically involved in assessment at the Centers included educational diagnosticians, special education teachers, clinical and school psychologists, and speech and language pathologists. Thurlow and Ysseldyke found that although technically sound instruments were available to professionals, many of the model programs were using for placement, tests that were either technically inadequate or otherwise irrelevant to the placement decision.

While Thurlow and Ysseldyke's study suggests that many model programs use questionable measures in the placement process, the study does not indicate the frequency with which such measures are employed. Ysseldyke (Ysseldyke, Algozzine, Regan, & Potter, 1980), in a second study, used a computer simulation to investigate the extent to which professionals use technically inadequate measures in making placement decisions. Subjects for the study were 159 school psychologists, special and regular education teachers, social workers, administrators, and other support personnel, who were presented referral information about a hypothetical child for whom they would have to make a placement decision. Subjects were told that the computer would provide, upon request, assessment results on the case from a variety of measures in each of seven domains. Participants were allowed to select from as many domains and as many measures within each domain as they found necessary. Results of the investigation showed that when professionals first accessed information about the case, they tended to select inadequate devices as frequently as adequate ones. In addition, their tendency to choose inadequate measures increased as more and more information about the case was accessed.

One reason for widespread use of technically inadequate assessment procedures was provided by Bennett (1980). This investigator examined the basic measurement competence of educational diagnosticians serving one state in the continental United States. Each of the 95 diagnosticians participating in the study possessed at least a master's degree, with the great majority (73%) citing special education as a major field of graduate study. Basic measurement competence was defined to include knowledge and ability to apply in the assessment situation such rudimentary concepts as those related to reliability, validity, norms, measures of central tendency and variability, criterion-referenced interpretations, and interpretive aids. Results of the study showed educational diagnosticians to achieve only an average of 50% correct on a 64-item test of measurement competence. In addition, diagnosticians performed significantly more poorly on the test than graduate students enrolled in an introductory measurement course. Bennett concluded that diagnosticians of the population studied were deficient in measurement competence and hence did not have the skills necessary for selection of appropriate procedures nor those needed for sensible interpretation of data routinely used in the identification and placement process.

If, as studies suggest, professionals are lacking in the competencies necessary for proper selection and interpretation of assessment tools, what effect might this deficiency have on the placement process? An indication of some possible effects is provided by the results of a research study and by documentation from a litigative action.

Garrison and Hammill (1971) compared students in regular and educable mentally retarded classes in the greater Philadelphia area to determine the extent to which children had been improperly placed. The results of tests of intelligence, social inference ability, reading skill, auditory reception, and verbal expression were analyzed for 378 EMR and 319 regular class pupils. Because of the nature of mental retardation, poor performance in all or most of the areas tested would be expected for the EMR children. Results showed that 25% of the EMR subjects and 88% of the regular class students performed above a minimal cutoff set by the authors in at least four of the five tested areas. In addition, 43% of the EMR pupils scored above the cutoff on two or three of the tests. Garrison and Hammill concluded that at a minimum, 25% of the children studied in the EMR group had been misplaced.

Diana v. State Board of Education (1970) was a class action suit filed on behalf of nine Mexican-American students, aged 8-13, who had been placed in classes for the educable mentally retarded. Each of the nine students came from a home in which Spanish was the primary language spoken. Initial placement in classes for the mentally retarded had been primarily based on the results of English language administration of a standardized test of intelligence. Upon retesting in Spanish, seven of the nine scored above the criterion for regular class placement, suggesting that erroneous placement of the children in EMR classes had occurred because of errors in the selection and interpretation of assessment procedures.

In sum, the limited data that exist on assessment competence and placement can be taken to suggest support for the following:

1. Assessment personnel may not fully possess the knowledge and skill necessary for proper selection and interpretation of assessment tools.

2. A lack of assessment knowledge and skill may have negative effects on the placement process (e.g., erroneous placement).

Conclusions and Recommendations

This paper has presented evidence which suggests that serious problems exist with regard to the competence of professionals involved in the educational and psychological assessment of exceptional children. The conclusion that problems exist in professional competence, however, needs to be tempered by a number of considerations. These include the fact that evidence supporting the existence of problems in professional competence is partially opinion and perception, that the research base on professional competence in assessment is relatively small, and that other problems in the assessment process may be, to some degree, confounded with issues of professional competence. An example of a particularly pressing issue that may be confounded with questions of competence is the problem of time (Kirp & Kirp, 1976), where long waiting lists, a lack of funds, and shortages of certified personnel force assessors to conduct evaluation in a rapid rather than careful manner. While the extent to which such factors are confounded with problems of professional competence needs to be further investigated, the weight of the available evidence suggests that deficiencies in assessment knowledge and skill exist in a significant number of professionals.

The effects of knowledge and skill deficiencies in even a small number of assessors are unfortunately severe. Such deficiencies can lead to test misuse and abuse which in turn can result in the provision of inaccurate data to those who must make decisions about the identification, classification, programming and placement of exceptional children. If professional performance is to be improved, and misuse of tests and other procedures reduced, specific areas of skill and knowledge in which improvement is needed must be specified. While some of these areas have already been identified (e.g., test scoring skill; basic measurement competence) for some groups of professionals, more efforts to identify specific knowledge and skill deficiencies for particular groups of assessment professionals need to be undertaken. Such a training-needs assessment approach is required for special education and related service personnel by the Rules and Regulations of PL 94-142 (U.S. Office of

Education, 1977) and has been advocated for use with assessment personnel by Bennett and Lewis (1979). The reader interested in a detailed treatment of this approach is referred to that article.

In addition to the implementation of a comprehensive effort to identify professionals' assessment training needs, an equally comprehensive attempt to provide inservice training for assessment personnel in areas of documented training need must be instituted and supported. The groundwork for such an effort has been laid by the mandate for a Comprehensive System of Personnel Development as specified by the Rules and Regulations of PL 94-142. This mandate sets up a structure and funding mechanism for inservice activity within which states may design and deliver training to special education and related service personnel. It is incumbent upon those responsible for statewide training efforts to insure that the training needs of assessment personnel are adequately provided for through this system.

Finally, mechanisms to insure continued high levels of competence for assessment professionals must be found. Miller and Engin (1974, 1976) have proposed the institution of non-permanent, periodically renewable certification for school psychologists and school counselors. Certification renewal in this system is based, in part, upon objective evaluation of knowledge, skill, and performance in those areas which make for success in the position. Bennett (in press) has provided an initial set of guidelines for such evaluation. Use of a "performance-based" system for encouraging a high level of competence for all groups of assessment personnel should be strongly considered.

Summary

This paper has argued that serious problems exist in the competence of professionals involved in the assessment of exceptional children. In support of this argument opinions and perceptions related to performance problems were cited, research on test scoring skill was reviewed, and documentation and research on pupil placement was discussed. Finally, recommendations for improving competence and performance through needs assessment, inservice education, and performance-based certification were presented.

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UNIT IV: COMMUNICATION

GOALS AND OBJECTIVES

Information Exchange and the Referral Process, Part I: Communication Strategies

Purpose:

To provide participants with appropriate strategies for communicating with the handicapped child/youth and others concerned with the delivery of educational and health-related services.

Specific Objectives:

At the conclusion of this session, participants should:

1. Be more sensitive to and accept the concerns of handicapped children and youth in dealing with "normal" daily routines of living and learning.

2. Be aware of the impact a child or youth with handicapping conditions can have on all family relationships:

   a. parental relationships
   b. sibling relationships
   c. parent/child relationships
   d. family/community relationships

3. Be more sensitive to the need for appropriate, supportive, communication strategies (verbal and nonverbal) when interacting with:

   a. a handicapped child or youth;
   b. parents of a handicapped or high risk child or youth;
   c. colleagues regarding the education and health-related services of handicapped children and youth;
   e. supervisors regarding the education and health-related services of handicapped children and youth;
   f. other health and related-services professionals, regarding the education and health-related services of handicapped children and youth; and
   g. special and regular educators regarding the education and health-related services of handicapped children and youth.

4. Understand and be able to implement appropriate, supportive communication techniques when interacting with:

   a. the child or youth with a handicapping condition;
   b. parents of the child or youth with a handicapping condition; and
   c. siblings of the child or youth with a handicapping condition.

5. Recognize the need to respect the parents' experiences with their child/youth and plan to utilize that expertise by totally involving them in the referral process.

6. Understand and be able to implement appropriate strategies for working with the parents in completing the referral process and preparing the parents to be the child/youth's case manager.

GENERAL SESSION III
(Unit IV)

INFORMATION EXCHANGE AND THE REFERRAL PROCESS

Part I: COMMUNICATION STRATEGIES

by
Carolyn M. Del Polito, Ph.D., Director
Allied Health Child Find and Advocacy Project
American Society of Allied Health Professions

I. The Communication Process: A dynamic, on-going, circular process in which the receiver attaches meaning to selected stimuli.

II. Models of the Communication Process
    A. Intrapersonal Communication
    B. Interpersonal Communication

III. The Client-Care System: The Participants
    A. Child or Youth
    B. Parents
    C. Siblings
    D. Colleagues
        1. Allied Health
        2. Education
            (a) Special Educators
            (b) Regular Educators
            (c) Administrators
        3. Health
    E. Supervisors
    F. Community Members

IV. Communication Barriers/Breakdowns
    A. Message Transmission Noise
    B. Semantic Noise
        1. Denotative Meanings
        2. Connotative Meanings
    C. Nonverbal Noise
    D. Stereotyping
    E. Defensive Listening

V. Improving Communication
    A. Social Sensitivity
    B. Active Listening
    C. Honest, Supportive Communication
        1. Acceptance of Self
        2. Acceptance of Others

"WHAT WE ACTUALLY DO WHEN WE SPEAK TO EACH OTHER IS TALK TO OURSELVES."

That is, when I talk to you, I'm actually talking to my hypothesis or estimation--my image of you.

"THE MORE I KNOW ABOUT YOU--THE GREATER THE PROBABILITY THAT I WILL TALK TO YOU, RATHER THAN TO MY IMAGE OF YOU. . . ."

"THE EFFECTIVENESS OF MY COMMUNICATING WITH YOU. . .'DEPENDS' ON HOW MUCH I KNOW AND UNDERSTAND ABOUT HOW YOU PERCEIVE YOURSELF."

Question: How can we get information from others about themselves to be able to truly communicate with them?

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from: John W. Keltner, Interpersonal Speech Communication, Belmont, California: Wadsworth Publishing Company, Inc., 1970, pp. 52-53.

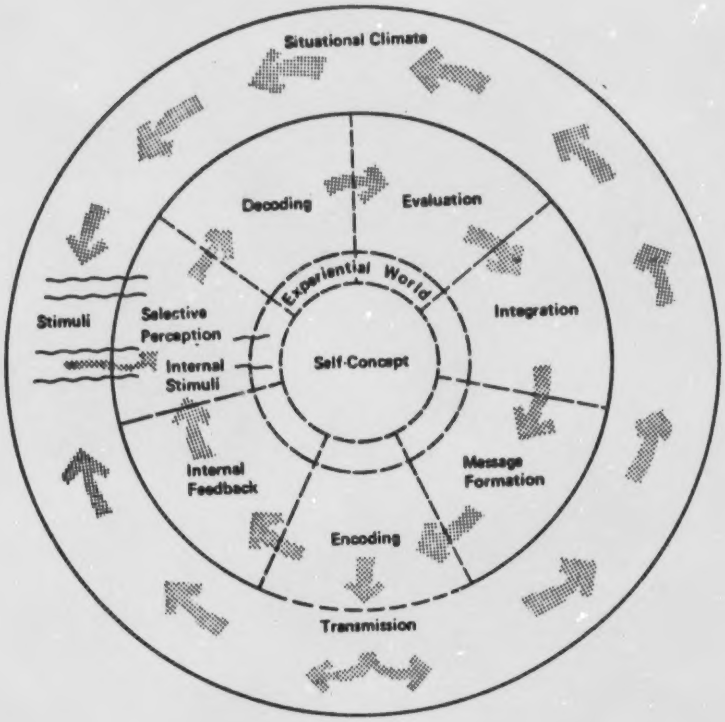
Situational Climate
Decoding
Evaluation
Experiential World
Integration
Stimuli
Selective Perception
Internal Stimuli
Self-Concept
Internal Feedback
Message Formation
Encoding
Transmission

Figure 1.1. The intrapersonal communication process.

Figure 1.1 illustrates the intrapersonal communication process. An individual's self-concept is at the heart of the process, since one's self-concept determines the stimuli selected and the way in which the stimuli will be decoded, evaluated, and integrated into the individual's self-system. The self-concept also determines the message to be transmitted and how it will be sent. As the dotted lines indicate, the self-concept affects and is affected by one's experiential world—all the information accumulated during one's lifetime, including cultural experiences, knowledge, abilities, beliefs, attitudes, and feelings, as well as needs, goals, and expectations for the future. In turn, the person's experiential world affects the entire process of intrapersonal communication. As Figure 1.1 indicates the process is ongoing, circular, and operates as long as stimuli from the situational climate (time, place, and circumstances) or experiential world bombard the individual.

from: Carolyn M. Del Polito. Intrapersonal Communication. Menlo Park, CA: Cummings Publishing Company, 1977, p.3.

SIX PRINCIPLES OF LANGUAGE

Count Alfred Korzybski, who coined the term general semantics (the study of any behavior which results from language habits), believed language to be a powerful influencer of our thinking and our behaving. The following six principles are derived from Korzybski's three basic principles of language: the principle of non-identity; the principle of non-allness; and the principle of self-reflexiveness.

1. WORDS SYMBOLIZE THINGS, BUT ARE NOT THOSE THINGS.
2. MEANINGS ARE IN PEOPLE, NOT IN WORDS.
3. AVOID SIGNAL RESPONSES TO SYMBOLS.
4. IT IS IMPOSSIBLE TO KNOW EVERYTHING ABOUT ANYTHING.
5. ALL THINGS CHANGE.
6. AVOID RIGID, NON-PROCESS ORIENTATIONS.

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from William D. Brooks, Speech Communication, Dubuque, Iowa: W. C. Brown Company, 1971.

DEFENSIVE AND SUPPORTIVE COMMUNICATION CLIMATES

DEFENSIVE BEHAVIOR: behavior which occurs when an individual perceives threat or anticipates threat.

Defensive behavior leads to defensive listening and produces postural, facial, and verbal cues which raise the defense levels of the orginial communicator.

Increases in defensive behavior have been found to correlate positively with losses in efficiency in communication.

DEFENSIVE CLIMATES	SUPPORTIVE CLIMATES
1. Evaluation	1. Description--genuine requests for information.
2. Control	2. Problem-Orientation--collaborate on seeking solution to problem
3. Strategy--hidden motivation	3. Spontaneity--straightforward and honest
4. Neutrality--little warmth or concern for the other person	4. Empathy--respect for worth of the other person
5. Superiority	5. Equality--mutual trust & respect
6. Certainty--dogmatic	6. Provisionalism--willing to experiment and investigate issues

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from Jack R. Gibb, "Defensive Communication", Journal of Communication, Volume XI, No. 3 (September, 1961), pp. 141-148.

LEVELS OF EMPATHY

Level I: Maximum Understanding through Social Sensitivity

- A. Understanding the Speaker's Perceptual World
    1. Attitudes
    2. Values
    3. Beliefs
    4. Knowledge
    5. Culture
    6. Social System
    7. Past Experiences
    8. Future Expectations
- B. Understanding Our Own Perceptual World--Selective Perception
- C. Understanding the Content Communicated--What is Being Said?
- D. Understanding the Feelings Communicated--How is the Message Being Said?

Level II: Confirmation of Understanding through Active Listening

- A. Attention During Communication
    1. Nonverbally (attentive posture, head nods, eye-contact, facial expressions)
    2. Verbally (vocalizations which indicate you're keeping up with the speaker and interested in the information communicated)
- B. Reflection of Maximum Understanding of Other's Ideas
    1. Verbally
    2. Nonverbally
- C. Reflection of Maximum Understanding of Other's Feelings
    1. Verbally
    2. Nonverbally

THE REFLECTIVE RESPONSE TECHNIQUE

Definition: A response by the listener in which he/she verbalizes back to the speaker the essential ideas and feelings the speaker has expressed. The listener acts as a mirror, reflecting back and supporting the speaker's message.

Objectives:

1. Listen not only for the words of the speaker, but for the feelings behind the words as well.

2. Try to see and understand the world through the speaker's perceptions.

3. Do not evaluate. Suspend your own value judgements, so as to understand the speaker's thoughts and feelings as he/she experiences them.

4. "Check out" your understanding by verbally and nonverbally reflecting back to the speaker the essential ideas and feelings the speaker has expressed.

5. Encourage further verbalization; support the speaker's ideas and feelings by providing additional information which you feel helps clarify the speaker's ideas and feelings.

6. The following phrases may help you get started with the reflective response technique:

   What you seem to be saying is . . .

   I think you're saying . . .

7. When sharing your own personal perceptions, use the "I Rule." Talk in terms of yourself; personalizing your conversation with yourself. The following phases may help:

   I feel . . .

   It is my opinion . . .

   I believe . . .

   To me it is . . .

   For myself . . .

   I think . . .

ACTIVE LISTENING

One of the most important skills in getting to know another person is listening. In order to get a check on your ability to understand what your partner is communicating, the two of you should use the Reflective Response Technique.

Decide which one of you will speak first.
The first speaker is to carry on and complete the following item in two or three sentences:
When I think about the future, I see myself . . .

The second speaker repeats in his/her own words the statement that the first speaker has just said. The first speaker must be satisfied that he/she has been heard accurately.

The second speaker then completes the item in two or three sentences. The first speaker paraphrases what the second speaker just said, to the satisfaction of the second speaker.

. . . .

At this point discuss with your partner what you have learned about yourself as a listener. From here on it is important that both of you try to listen and understand one another as fully as possible, If at any point either of you feels this is not happening, you should stop. Try to determine why you have stopped communicating, discuss the situation as fully as possible and then continue.

. . . .

1. I am happiest when . . .
2. When I am alone I usually . . .
3. In large groups I usually . . .
4. I believe in . . .
5. The thing that turns me off the most is . . .
6. I love . . .
7. The thing that turns me on the most is . . .

. . . .

Have a two or three minute discussion about this experience so far.
Try to cover the following points:
How well are you listening?
How open and honest have you been?
How eager are you to continue this interchange?
Are you getting to know each other?

. . . .

8. The emotion I find most difficult to express is . . .
9. My strongest point is . . .
10. Expressing feelings makes me feel . . .
11. My weakest point is . . .
12. Getting to know new people is . . .

SOME COMMON LISTENING PROBLEMS*

1. Viewing a Topic as Uninteresting.
2. Criticizing a Speaker's Delivery Instead of His Message.
3. Getting Overstimulated or Emotionally Involved.
4. Listening Only for Facts.
5. Preparing to Answer Questions or Points Before Fully Understanding Them.
6. Wasting the Advantages of Thought Speed Over Speech Speed.
7. Trying to Outline Everything.
8. Tolerating or Failing to Adjust to Distractions.
9. Faking Attention.
10. Listening Only to What is Easy to Understand.
11. Allowing Emotionally Laden Words to Interfere with Listening.
12. Permitting Personal Prejudices or Deep-Seated Convictions to Impair Comprehension and Understanding.

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* from Larry L. Barker, Listening Behavior, N.J.: Prentice Hall, 1971.

COMMUNICATION: EFFECTS ON SELF-CONCEPT

Carolyn M. Del Polito, Ph.D.

As we examine self-concept theory, four basic propositions emerge which focus attention on the importance of our communication with others:

1. Self-concept (one's total perceptual appraisal of oneself--physically, socially, academically, and psychologically) guides and directs behavior.
2. An individual's self-concept can be modified or changed in certain social interactions.
3. Although there are a variety of ways self-concept develops (e.g., labeling dominant behavior patterns, and social comparisons), self-concept develops primarily through interactions (communication) with others.
4. The more influential interactions are those involving significant others--those persons who reinforce the individual's perception of him/herself.

Since the Allied Health professional may provide feedback to children and youth regarding their skills and abilities through both verbal and nonverbal interactions, the Allied Health professional can become a major significant person in the development, maintenance, and hopefully enhancement of the child's self-concept. The Allied Health professional's role in health care delivery becomes BASIC to how children and youth perceive themselves and their disability, which in turn is BASIC to their behavior in other aspects of their lives.

We need to make certain we help ENHANCE the child's self-concept, realizing that an enhanced self-concept in NOT an inflated view of oneself, but rather a realistic perception of one's strengths and weaknesses, and an acceptance of that perception.

The guidelines which follow should be considered by the Allied Health professional in his/her interactions with children and youth with handicapping conditions to enhance their self-concepts.

SELF-CONCEPT ENHANCEMENT AND COMMUNICATION

Carolyn M. Del Polito, Ph.D.

Health Provider Guidelines

1. Facilitate client-centered case management. Actively assist children and youth to see themselves as planning, purposing, choosing individuals, responsible and accountable. Children can grow, flourish, and develop much more readily when the significant person "projects an inherent trust and belief in their capacity to become what they have potential to become" (Hamachek, 1971, p. 202).

2. Help children and youth identify their own particular needs, interests, and concerns; help maximize success. Not all children will be motivated in the same way or interested in the same things; health provider needs to make success more available in more different ways.

3. Personlize your interactions. Appear sincere, uncalculating, and attuned to disabled youngsters as individuals.

4. Provide the youngster with flexible, yet definite goals for success. When limits are clear, the individual learns to rely on his/her own judgements and interpretations of events and consequences. This is particularly important for the highly anxious child who requires a structured situation in which to operate.

5. Highlight the child's specific strengths, assests, and skills to aid the individual in sorting out his/her own strengths and weaknesses. The child needs to know his/her own capabilities in order to gauge the probility of success.

6. Alleviate ambiguity, disrepect, and rejection in your interactions with children and youth.

7. Maintain an atmosphere of warmth and acceptance. The more positive the child's perceptions of your feelings toward them, the more positive their self-image, the better their achievement, and the more desirable their behavior.

8. Praise yourself. Recognize and acknowledge your own strong points in the presence of your clients. Your recognition of your own strong points will provide an impetus for your clients to praise themselves.

9. Do not prejudge your clients. Be honest and accurate in your evaluations, while avoiding comparisons with peers. Your expectations for a performance is a significant determinant of how the child actually responds.

10. Personalize evaluative comments, giving encouragement to clients. Evaluation, whether verbal or nonverbal, which is more personal, in which the evaluator appears to take into consideration every action, attends to subtleties in behavior and modifies his/her appraisal accordingly, should have a greater impact on the child's self-concept.

11. Provide children with a continuous, long term exposure to a particular appraisal. From a credible and personalistic source, it should have profound effects on self-concept.

12. Provide experiences for each client to receive acceptance from peers whenever possible.

13. Provide experiences for clients to praise others. Persons with high self-esteem show greater acceptance of others.

14. Help children to evaluate themselves realistically. Evaluation should be based on the child's comparison of his/her actual performance with his/her own personal standards.

15. Urge clients to concentrate on improvement, rather than perfection.

16. Provide experiences for children and youth to praise themselves. Self-accepting individuals tend to have higher self-concepts. Positive self-evaluation in the form of verbal reinforcements is positively related to self-concspt.

SELF-CONCEPT ENHANCEMENT*

General Guidelines

To facilitate growth and learning through self-concept enhancement, we must:

1. Understand that we communicate what we are, not just what we say. We communicate our own self-concepts far more often than we communicate information (subject matter).
2. Understand that anything we do or say could significantly change an individual's attitude about himself/herself for better or for worse. We must understand the implications of our role as persons who are important or "significant" to others if we are to utilize that role properly.
3. Understand that individuals behave in terms of what seems to be true, which means many times communication occurs, not according to what the facts are, but according to how they are perceived.
4. Be willing to deal with what a message means to different people. In the truest sense of the word, we must be willing to deal with the interpretation of a subject as we are to deal with the information about it.
5. Understand that we are not likely to get results simply by telling someone he/she is worthy. Rather, we imply it through trust and the establishment of an atmosphere of mutual respect. One good way to start is to take time to listen to what others have to say and to use their ideas when possible.
6. Understand that behavior which is distant, cold, and rejecting is far less likely to enhance self-concept, than behavior which is warm, accepting, and discriminating.
7. Be willing to be flexible in your communication with others.

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* Adapted from -- D. Hamachek. Encounters with the Self. N.Y.: Holt, Rinehart & Winston, 1971.

UNIT IV: COMMUNICATION

RESOURCES

- Effective Communication Strategies from Action Through Advocacy, Research and Training Center in Mental Retardation, Texas Tech University, 1980.
- Tips for the Allied Health Professional Interacting with Handicapped Children and Youth.
- The Practices of a Good Listener.
- Bridging the Parent/Professional Communication Gap - adapted from "How To Get Services by Being Assertive" by the Coordinating Council for Handicapped Children.
- Collaborative Problem Solving Planning for Children with Developmental Problems, by Mark N. Ozer.
- Assessing Parental Capabilities, from The Physician & Mental Health of the Child, by the AMA, 1979.
- Children and Family Assessment: The Family Inventory, from The Physician & Mental Health of the Child, by AMA, 1979.
- Perception of Self and Others

Listener Responses

Immediately after the average person has heard someone speak, he or she remembers only about half of what was said. Instead of focusing our attention on the speaker, we allow our thoughts to wander, and sometimes they never return to the conversation. How many times have you missed a speaker's message because you were mentally planning a trip or making a shopping list instead of listening?

You can improve your listening habits by developing a few basic skills. One essential skill is the ability to block out distractions. You must be able to concentrate on the ideas being presented in spite of background noise, uncomfortable seating, or preoccupation with your own thoughts.

Good listening requires much more than passively letting sound waves enter your ears. You must be as actively involved as the speaker. While you listen, try to identify the speaker's main ideas and decide which are most important. Compare the speaker's attitudes and opinions with your own. Select the points which you feel are worth remembering and then try to relate them to your own experience.

The response you give to a speaker determines whether your communication continues. Some responses, even when the responder means well, cut off further communication. Such responses include evaluation ("You should . . .," "You are wrong . . ."), advice ("Why don't you . . ."), direction ("You have to . . ."), moralizing ("You ought to . . ."), criticism ("If you had only . . ."), analysis ("What you need is . . ."), and one-upmanship ("You think your problem is bad, you should hear about mine"). These evaluating and criticizing responses make people defensive and resistant to sharing more. The advising and directing responses cut off communication by "solving" and thereby ending the problem. They also prevent the speaker from working out his or her own problem through further talking.

There are basically five ways you can respond to a speaker if your goals are to understand and to encourage the speaker to continue.

1. **Passive listening**

   Passive listening simply lets the speaker know you are still "with" him or her. Several nonverbal signals will encourage the speaker to continue—nodding your head, smiling, and leaning forward. Typical verbal responses used to show you are paying attention include "I see," "really," "yes," and "mm-hmm."

2. **Paraphrasing**

   Paraphrasing is one way to check your understanding of the speaker's ideas. Restate what the speaker has said, using your own words. This is most appropriate when the speaker pauses and is waiting for you to comment. For example:

   Speaker: No matter what I do, my teacher puts me down. I guess I can't do anything right!

   Listener: Am I getting this right? You're beginning to feel like a failure because nothing you do seems to please your teacher.

3. **Echoing**

   When the speaker clearly describes an emotion, restate the idea using the speaker's own words.

   Speaker: I feel scared when I meet new people. Everyone stares at me.

   Listener: You feel scared when you meet people and they stare at you.

4. **Dialogue sustaining**

   If a speaker seems to need reassurance that you are interested, try a response such as, "I'd like to hear about that." When you need more information, dialogue sustaining responses such as, "I'd like to know more about that," and saying "and" or "but" with a questioning inflection may encourage the speaker to continue talking.

   Speaker: I *was* planning to get a job . . .

   Listener: But?

   Speaker: But my mother says she doesn't have time to take me to work and I can't drive.

5. **Active listening**

   Active listening is providing feedback on the emotion the speaker seems to be experiencing. Your feedback helps the person to get in touch with his or her feelings and then to work out solutions independently. Your feedback should be on the same emotional level as the speaker's original statement. Some lead-in phrases you can use are: "You seem to feel really ___________," "Kind of makes you feel ___________," and "It sounds as if you feel sort of ___________ right now."

Speaker: Everybody tells me what to do! I wish just once I could do what I want to.

Listener: I gather you're pretty irritated right now.

Active listening takes time (it would be quicker to evaluate the speaker's feelings and give advice). So don't use it unless you really want to help the person and are willing to take the time. Active listening also means accepting the speaker's feelings without moralizing or trying to change the person.

These responses show a speaker that you are listening. Consciously using these responses also helps you pay attention to the conversation.

TIPS

1. Block out distractions.
2. Think while you listen. Identify the speaker's most important points and relate them to your own ideas and experiences.
3. Suspend your judgment for a while and try to understand the speaker's point of view.
4. Resist evaluating, criticizing, giving solutions, or moralizing.
5. Use one of the five positive listener responses:

   passive listening
   paraphrasing
   echoing
   dialogue sustaining
   active listening

Effective Communication Strategies

Your effectiveness as an advocate depends largely on your ability to communicate, that is, to send and receive messages accurately. You must be able to communicate first of all with your protege or client. Since you are supposed to represent his or her interests as though they were your own, you need to be able to determine what those interests are. Some developmentally disabled people have communication handicaps, such as hearing or vision impairments or limited intelligence, and you may need special techniques to help them express themselves and to understand them. You also must be able to communicate with the people, such as teachers, service providers, and administrators, who have the power to make the necessary changes for your client or protege.

Good communication involves more than just talking. It depends on verbal and nonverbal factors, such as voice quality, pronunciation, vocabulary, grammar, gestures, facial expression, interpersonal skills, and attitudes. You can improve your communication skills by becoming aware of some of the techniques of effective communication.

Interpersonal skills

A good relationship between two people increases the chance for communication. You listen better if you care about the person who is speaking; also, you are inclined to be open and honest if a listener is responding with respect and understanding. When you let the other person know that you think he or she is a worthwhile person, you create trust. Thus, your attitudes about another person affect how well you communicate. Whether your relationship is personal or professional, communication is more likely to take place if you relate to the other person with empathy, respect, and authenticity.

Empathy

Empathy is recognizing another person's feelings. This is different from sympathy, which is compassion or condolence. Empathy, in effect, is saying, "I may not feel the same way, but I do recognize how you feel." *Being* empathetic is not enough; you must be able to convey your understanding. Here are some ways that you can communicate empathy.

Before you begin to understand how someone feels, you must give him or her your undivided attention. When your protege or client is telling you something, don't let personal problems or irrelevant thoughts distract you.

You can communicate your attentiveness and concern through your nonverbal behavior. Face the person directly, lean slightly forward, and look at the person's eyes.

Responses such as "Yes," "I see," or "mm-hmm" or nodding your head and smiling will encourage a person to continue talking. Silence may be interpreted as indifference or disapproval. Respond frequently and honestly. Don't say "I see" when you don't really understand. To check your understanding, paraphrase what the person has said and preface it with a question such as, "Do I have this right?"

Respect

Respect, the second crucial ingredient in a good relationship, is the unconditional acceptance of another person's behavior, beliefs, opinions, and feelings. This is a "no strings attached" attitude; your continued regard is not based on the person meeting your standards of behavior or beliefs. Acceptance is not the same as agreement. You can disagree with someone and still accept that person's right to his or her own opinions.

Being accepting is sometimes hard to do. Most of us have prejudices, whether we are aware of them or not. You don't have to condone a person's lifestyle, beliefs or behavior, but you should respect his or her right to choose how to think and act.

You can show respect by following the guidelines for communicating empathy. People will feel respected if you listen attentively and check your understanding by asking questions. Avoid arguing, trying to prove that only your ideas are right, and jumping to conclusions before you have enough information.

Showing respect also requires a nonjudgmental attitude. Criticisms such as "Why don't you act your age?" and "That's not the way you're supposed to behave" will usually only cause resentment. Your protege or client will feel accepted and understood if instead of

From: Action Through Advocacy, Research and Training Center in Mental Retardation, Texas Tech University, 1980.

saying, "You shouldn't feel that way," you say, "I can see why you might be angry. Maybe we can think of some things you can do to help the situation."

You can convey respect verbally, but if you are not sincere, your nonverbal behavior can convey your disapproval, embarrassment, repulsion, or insincerity. Nervous fidgeting, blushing, frowning, avoiding eye contact, staring, or moving away from the person will make your true feelings obvious. Nonverbal behavior that shows acceptance and warmth includes smiling, touching, moving closer, eye contact, and relaxed body posture.

Acknowledging your protege's or client's strengths and abilities also shows respect. Your relationship should be a partnership with each of you contributing equally. Patronizing or dominating your protege undermines this relationship. Common forms of patronizing include insincere praise, excessive sympathy, giving unwanted advice, or insisting on doing things for a person that he or she is capable of doing. The dominant "I know what's best for you" attitude is communicated by frequent interruptions, arguments, lectures, and changes of the subject. If all of your communication is to provide solutions and advice and to impose your own ideas, you belittle your protege's ability to accept responsibility. Your respect motivates your protege or client to seek answers to his or her own problems.

Authenticity

Being authentic means being natural, open, and nondefensive. However, it does not mean that you reveal all of your thoughts and feelings all of the time; those you do choose to express must be genuine. Sharing positive feelings with your protege is almost always appropriate, but revealing feelings of anger, disgust, and frustration requires a high degree of trust in your relationship. When you feel it is necessary and appropriate to discuss your negative emotions, phrase them tactfully and in a way that does not blame or criticize your protege: "When you did this, I felt ________. Did you realize that was how I felt?"

Relating your personal experiences, when they are relevant to your protege's problem, is another way to communicate authentically. For example, when your protege is having trouble at work, you might respond, "I remember how uncomfortable I felt when my boss and I had a disagreement." Then go on to explain the incident. Share information about your experiences sparingly and only when relevant to your protege's needs, or it may seem that you are trying to impress your protege with your own accomplishments.

Discrepancies between your verbal and nonverbal behavior may reveal a lack of authenticity. If your conversation is all pleasant and positive, but you tap your fingers on the table, wear a forced smile, and fidget, people will perceive you as dishonest and insincere. Body language can be effective in conveying your genuine care and concern. A pat on the back, a hug, or shaking hands may be an appropriate way to express your feelings if physical contact does not make your protege uncomfortable.

TIPS

1. Pay attention to your protege or client or to anyone else with whom you are interacting.
2. Check your understanding of what a person is saying.
3. Accept the other person's right to his or her own feelings and beliefs.
4. Acknowledge your protege's or client's strengths.
5. Share positive feelings.
6. Be honest.

Nonverbal Communication

As we interact with others, we constantly send nonverbal messages through our body movements, facial expressions, and gestures. The ability to send these nonverbal signals is innate, but nonverbal communication is also a skill that can be improved through practice.

Personal space

One of the nonverbal ways we communicate our relationship to people is by the distance we keep between us. We each have an invisible personal territory surrounding us, called personal space. The boundaries of your personal space contract and expand depending on your emotions, the activity you are involved in, your cultural background, and whether the relationship is intimate, personal, social, or public. Most of your daily communication occurs in the personal and social zones. During conversation, people usually maintain a personal distance of two and a half to four feet. At social gatherings, the appropriate distance for conversation increases to four to seven feet.

People are very disturbed by intrusions into their personal space. If someone gets too close to you, you feel nervous and uncomfortable. You may try to move away but when that is not possible you tense your muscles and possibly turn your head away. As a last resort, you may try to protect your space by placing an object such as a purse or a briefcase between you and the other person.

Eye contact

Eye contact is also an important nonverbal signal. When two people look at each other and smile or nod, this is usually understood to be a joint agreement to begin a conversation. As a good listener, you look at the other person's face, especially the eyes; looking away indicates that you are ready to end the conversation. The amount of eye contact you use can communicate emotions and attitudes. Avoiding eye contact conveys shame, embarrassment, anxiety, or a lack of confidence. The more eye contact you have, the more likely the other person will be to see you as friendly, mature, and sincere. However, this is only true up to the point where a normal gaze becomes a stare. Staring may make the other person feel nervous and defensive because it is seen as a sign of contempt or disapproval. To stare at someone is equivalent to saying, "I'm better than you" or "I don't approve of what you're doing."

A word of caution about interpreting eye contact: the rules for appropriate eye contact vary with sex, class, age, and culture. So, when another person avoids looking at you, for example, he or she may actually be frightened, embarrassed, depressed, or nervous or may simply belong to an ethnic group with different visual customs. For example, black children are taught to lower their eyes as a sign of respect for teachers and ministers.

Gestures

We use many different kinds of body movements to support our verbal communication. Some of these movements are conventional gestures such as a head nod for "yes." Other movements are unique to an individual or a situation (for example, a fraternity's secret handshake). Body movements serve two basic purposes for communication: they help to clarify the speaker's ideas or they express emotions and attitudes. Descriptive gestures help to illustrate objects or actions that are difficult to explain with words alone. You might use descriptive gestures to demonstrate how to kick a football, how to hold a baby, or how to eat with chopsticks. Gestures might also help you to tell someone how long the fish was that got away, how tall a basketball player is, or how you narrowly avoided an accident.

Most gestures associated with emotion are spontaneous and are not primarily intended to communicate. When you are tense, you may run your fingers through your hair, clutch the arms of the chair, play with an object, or move about aimlessly. Some gestural messages about emotion are sent deliberately—clapping to show approval or shaking your fist in anger.

Condescending gestures—such as patting the head of a mentally retarded adult—will damage a relationship.

Touching

Touching is another way we use our bodies to communicate. Greetings, farewells, and congratulations usually include physical contact. Touch may also be used to attract someone's attention so that you can begin a conversation. Society defines the type of touching which is appropriate to a particular situation. For example, your culture may require you to greet someone by shaking hands, rubbing each other's noses, kissing, or embracing. Even though you are limited by cultural rules of behavior, you can still convey personal attitudes through touch. Usually, you initiate more body contact when you like a person and feel comfortable with him or her. People tolerate different amounts of touching, however, so be sure that you are not intruding into the other individual's personal space. Touching can be an effective way to communicate positive feelings if you are sincere and the contact does not make either person uncomfortable.

Facial expression

Perhaps the most important and the most carefully controlled nonverbal signal is facial expression. The face can display a world of emotions—happiness, anger, surprise, sadness, fear, disgust. Appropriate facial expressions can help you convey your ideas and attitudes more accurately than words alone. Yet, most of us have been taught not to show our feelings, especially if they are negative, so we adopt a deadpan facial expression. Expressing extreme rage may not be helpful, but it is certainly less confusing for your listener if you let your face show a degree of irritation rather than smiling while the rest of your body signals tension and anger.

Nonverbal language of handicapped people

Handicapped people send nonverbal messages, as well as receive them. Physical or mental disabilities, or a lack of experience, may prevent people from displaying socially acceptable nonverbal signals, especially those which are used to convey liking. Their body language may give the impression that they are bored, indifferent, or even hostile. Misinterpreting these unintentional and sometimes peculiar behaviors may affect the way you react to handicapped people. Appearance and behavior may conflict in a puzzling way. When a person's appearance sends the message, "This is an adult," we unconsciously expect adult behavior and we may be frustrated when the person doesn't meet this expectation.

Summary

Your ability to send and receive nonverbal messages accurately can be a positive asset in your relationships with other people. You are communicating all the time, even when you are not actually talking.

TIPS

1. Keep the distance between you and the listener appropriate to the relationship and situation.
2. Maintain casual and warm eye contact without staring.
3. Use gestures and facial expressions that are consistent with your meaning and feelings.
4. Use handshakes, pats on the back, and hugs to reinforce positive feelings when you and another person feel comfortable with these contacts.
5. Interpret a handicapped person's nonverbal language cautiously.

Communicating with a Mentally Retarded Person

The effects of mental retardation on speech and language development may be so mild that the person has no speech problems or only minor articulation errors; or the effects may be so severe that the person will never develop functional speech.

Some people who lack *expressive* language (ability to speak, write, or gesture) have *receptive* language (ability to understand what is said to them).

Assess your protege's or client's verbal skills with an open mind. If the person has normal skills, you may not need to adjust your usual communication style. But if there are limitations, you must make extra efforts so that the protege will understand the issue and so that you will understand his or her point of view.

To avoid simply imposing your views on a retarded person, you need to take the time to explain and to listen.

Work with the person's parents, teachers, and social workers, and with the advocacy staff for suggestions on effective methods of communication. Being consistent with others who interact with the person will help him or her learn.

Some mentally retarded people have communication problems because their environments are limited. You will help them gain language ability and social interaction skills by letting them experience many normal activities.

TIPS

1. Try to keep your surroundings free from distractions. Remove any unnecessary objects in the area and keep background noise to a minimum. For example, turn off the radio and shut the window to reduce street sounds.

   If the person is too distracted by things happening in the room, you may need to move to another room or change location within the room. For example, in a busy coffee shop you might move to an isolated corner or sit with your backs to the activity.

2. Establish eye contact before you begin to speak, and maintain it as long as possible.

   Say the person's name often.

   Touch the person lightly on the arm or shoulder when you seem to be losing his or her attention. It may be necessary to move the face of a severely mentally retarded or highly distractible person toward you.

3. Speak expressively with appropriate gestures, facial expressions, and body movements. These nonverbal cues add information that make your ideas easier to understand. For example, when you say, "Let's go eat," to a person with a limited understanding of speech, you might gesture spooning food into your mouth.

4. Communicating with a person who does not have expressive language and who does not seem to respond to what you say requires frequent sensory cues. For example, mimic the activity you are talking about with gestures, physically move the person's hands, head, or feet to perform the activity you are describing, and try to get eye contact. Touch, hug, and pat in order to guide and affirm, combining these cues with the appropriate verbal comments. Resist your impulse to stop talking. Even if there is no apparent response, hearing your speech is good training for the retarded person.

5. Speak slowly and clearly, but don't exaggerate the inflection or tone of your voice. Exaggerations call attention to themselves rather than to what you are saying and are distracting and confusing.

6. Speak in "here and now" concrete terms. Give specific examples and demonstrate whenever possible. Instead of saying, "It's time to clean up" say, "Wash your hands in the bathroom now." Refer to "chair" instead of "furniture"; "apple" instead of "fruit"; "Mrs. Smith" instead of "your teacher."

7. Emphasize key words. For example, say, "Please bring me the *blue* glass."

   Repeat important statements, and use different words if the listener does not understand.

8. Be positive in giving directions. Instead of saying "Don't kick," say, "I'd like you to keep your feet on the floor." In this way you give the person a goal rather than calling attention to (and possibly reinforcing) inappropriate behavior.

9. Give directions immediately before the activity to be performed and avoid lists of things to do. If you say before you go into a restaurant, "When we get in the restaurant, you will first need to wash your hands, then come back to the table and unfold your napkin . . .," the retarded person may not remember and act on these directions without prompting. Instead, give the directions one at a time when you want the task performed.

10. Check frequently to be sure the person is understanding. It is pointless to ask, "Do you understand?" Instead, ask the person to repeat what you have said or ask a question that requires a specific answer, such as, "What are you supposed to do tomorrow?"

11. Ask open-ended and either-or questions rather than questions that can be answered with *yes* or *no*. Retarded people have a tendency to say *yes* when given a choice of yes or no, so such a response does not necessarily give you the right information. Instead, let the person describe a situation or give a choice of answers neither of which is obviously the right one. Be sure the alternatives you give cover all the possible situations.

    Examples

    yes-no question

    Did the man bite your arm?
    (the response will likely be yes)

    open-ended question

    Tell me what happened this morning.
    (the person must describe the situation)

    either-or questions

    Did this problem happen today or yesterday?

    Are you talking about a man or a woman?

    (neither alternative is obviously better; therefore the choice the person makes is likely to be accurate)

12. Don't pretend to understand. It is better to ask the person to repeat what he or she has said several times than to agree with something you don't understand. (You may be unpleasantly surprised when you find out what you have agreed to!) Say, "Tell me again." If you don't get a completely understandable answer, build from a particular point you can confirm. For example, ask, "Am I getting this right? This morning someone bit your arm."

13. Smile, nod, and lean forward while the speaker is talking. These signs that you are interested encourage the person to continue.

14. Be prepared to wait. The person with mental retardation may function slowly. Do not anticipate the speaker's response and finish sentences for him or her. Sometimes suggesting a key word the speaker is having trouble with will help the speaker keep going, but retarded people need to gain experience and confidence in their own speech.

15. When you note signs of fatigue, irritability, or disinterest, it is a good idea to change activities, slow down, make the task simpler, or take a break. One such sign is increased distractibility. Another sign is continued repetition of a response when it is no longer appropriate (for example, "want to go home," "time to go home," "want to go home").

16. Don't give a choice if you are not sincere. For example, don't say, "Would you like to come with me?" if the person *must* go with you. Instead say, "Let's go back to the cottage now." Giving choices when there are real options is good, though, because it reinforces decision-making. For example, say, "Would you like to come with me or would you like to stay at school?"

17. Sometimes the speech or behavior of a retarded person will be bizarre or otherwise inappropriate. The reason may be either lack of information and social skills or desire to get attention. How you respond will depend in part on the reason.

It is important to correct inappropriate speech or behavior resulting from lack of information. If you don't correct it you are essentially giving your approval and increasing the likelihood that it will happen again. For example, if a retarded person on a public bus begins to pat a stranger, try to divert the retarded person's attention and break the chain of events. You might do this by saying, "Please bring me my purse." Then explain with empathy and with regard for the person's self-esteem what the appropriate behavior is. For example, say, "That little girl you were touching is pretty, isn't she? But people don't touch each other until they are good friends. See how all the other people on the bus are holding their hands in their laps."

If the inappropriate behavior or speech is attention-getting, ignore it and direct the person to an appropriate topic or task. You might walk away, continue with what you are doing, repeat what you have been asking, or ask the person to do something that will interrupt the behavior or speech.

Give the person abundant attention when he or she behaves and speaks appropriately to diminish the need for negative attention.

18. Treat adults with mental retardation as adults, not as children. Use their proper names, and show respect when you introduce them to others. Consider the varying degrees of respect conveyed by the following introductions:

    "This is Billy. He's retarded."

    "This is Billy."

    "I'd like you to meet Bill Brown."

    When you praise an adult, do it appropriately. "You did a fine job" is certainly more appropriate for an adult than "That's a good boy." Avoid talking down to a retarded adult.

19. Talk *to* the mentally retarded person, not *about* him or her. No matter what the person's level of understanding, it is rude to discuss a person when he or she is present.

Communicating with a Hearing Impaired Person

Although some hearing impaired people possess adequate speech for basic social expression, those with profound hearing losses often do not learn to speak intelligibly. Thus, many deaf persons use written or manual communication as a supplement to or substitute for speech.

The term *manual communication* refers to several systems in which hand or body movements represent ideas, objects, actions, etc. If an idea cannot be expressed through manual signs, it is fingerspelled. *Fingerspelling* consists of twenty-six handshapes that correspond to the twenty-six letters of the Roman alphabet. Fingerspelling differs from *sign language*, which uses hand movements for words and phrases rather than single letters. To aid them in understanding the speech of others, hearing impaired people may rely on visible speech cues, facial expressions, and gestures, as well as the language and situational context. This method of using vision to partially compensate for hearing loss is called *speechreading* (formerly called lipreading).

Whatever special communication techniques your protege or client employs, there are several things you can do to make your communication more effective.

TIPS

1. The room should be sufficiently quiet to permit your voice to be heard with little difficulty. If there is background noise, such as footsteps, conversational babble, traffic rumbling by, loud heating and cooling units, minimize it as much as possible (close windows, turn off furnaces, move to a quieter room). Background noise may prevent the hearing impaired person from using residual hearing. Echo is less of a problem in small rooms and in rooms with carpet and drapery.

2. Position yourself directly in front of the person to whom you are speaking, rather than behind or to the side of him or her. Keep the distance between you as small as possible. Speechreading is easiest at five feet or less.

3. Try not to stand in front of a light source (for example, a window). Light behind you may throw shadows on your face and distort the normal movements of your mouth. The light should shine on your face rather than in the eyes of the person attempting to understand you.

4. Establish eye contact before you begin to speak. You may need to attract your listener's attention with a light touch on the arm or shoulder.

5. Provide a clear view of your face. Avoid actions which hide your mouth and reduce the accuracy of speechreading: resting your head on your hand, turning your head, waving your hands, smoking, chewing, and holding things in front of your face. Certain physical features can also affect speechreading. A moustache or beard may hinder speechreading by partially obscuring the mouth; lipstick may define the lips and enhance speechreading.

6. Speak clearly but naturally. Use your normal speed and loudness level unless asked to change. Speakers sometimes use a very slow rate, exaggerate their mouth movements, or shout, hoping to improve understanding. Actually, these efforts are more confusing than helpful.

7. Speak expressively; use gestures, facial expression, and body movements to convey mood and feeling. Deaf persons may misunderstand figures of speech ("the foot of a mountain"), puns, and sarcasm because they cannot hear the accompanying variations in tone, inflection, and stress. Thus, shrugging your shoulders, raising your eyebrows, or shaking your fist may relay an idea more accurately than words alone. Avoid exaggerated gestures, however, because these distract the attention of the speechreader from the basic point of focus—the face.

8. Use short, simple, complete sentences. Keep your language precise and concrete, rather than abstract. A general term such as "food" is more abstract than the word "apple," which refers to a specific fruit. Abstract words have vague meanings (for example, "nourishment in solid form"), which are difficult for the hearing impaired

person to grasp. Words which have many different meanings, such as "great," "down," and "over," are also confusing to the hearing impaired individual.

9. Repeat key words and statements and avoid changing the subject abruptly. Check comprehension frequently by asking questions or asking the listener to repeat what you have said. Deaf persons may pretend to understand when they do not (just as many hearing people do). When a hearing impaired person joins a group, make sure he or she knows the subject being talked about.

10. When a hearing impaired individual has difficulty understanding an important point, rephrase the idea rather than repeat the same words. Only one third of English sounds are visible to the speechreader. Words such as "king" and "her" cannot be speechread because they contain sounds which are produced by hidden movements inside the mouth. Many of the sounds which are visible are homophenous; that is, they look exactly like one or two other sounds. Therefore, the words "Pete," "beet," "mean," "bead," "bean," and "meat" appear the same to the speechreader.

11. If your listener is able to use some residual hearing, you may find it useful to lower your pitch somewhat. A high pitched voice (usually a woman's voice) is more difficult to understand.

12. Lacking the auditory feedback we use to monitor our own voices, the severely hearing impaired person may develop speech which is excessively loud, high pitched, monotonous, breathy, and nasal. If you have difficulty understanding a hearing impaired speaker, ask an open-ended question (for example, "Would you tell me about your family?"). A lengthy answer may give you time to become accustomed to the person's speech and language patterns. When you cannot understand a statement, ask the person to repeat or elaborate on what he or she has said. If this fails, a gestural or written mode of communication may be more effective than speech.

13. Do not assume that a deaf person's communication problems indicate a lack of intelligence. A profound hearing loss disrupts language acquisition to such an extent that deaf adults rarely have the verbal skills of a hearing 10-year-old child. The most obvious deficits in the language of the hearing impaired are a limited vocabulary and difficulty with syntax (arranging words into sentences). Reasons often cited for these problems are a lack of language stimulation and the fact that the syntactic rules of American Sign Language are quite different from the rules of English.

14. If you know any sign language, ask the person with whom you are talking if he or she would like for you to use it. Some people prefer to communicate through speech alone. Even if both of you agree to use signs, you may have difficulty communicating if you have learned different systems. Sign systems currently used in the United States include: American Sign Language (ASL), Systematic Sign Language, Signing Exact English, Seeing Essential English, Linguistics of Visual English, Signed English, and Manual English.

15. If your protege or client communicates primarily through signs and fingerspelling, and you are not familiar with this method, an interpreter may be necessary. An interpreter simply translates the conversation; he or she does not think or answer for the hearing impaired person. When using an interpreter, look at your protege or client and carry on the conversation as if talking to a person with normal hearing.

16. Watch for signs of fatigue in your listener. Following a conversation requires greater effort on the part of a hearing impaired individual, and the stress may make him or her tired, irritable, and tense. In addition, *tinnitus*, a noise or ringing in the ears, may be so annoying that it increases fatigue.

GUIDELINES FOR HOSPITAL POLICY FOR HEARING IMPAIRED PATIENTS

I. A central office should be designated to supervise services to deaf patients. This office should determine policy for provision of services to deaf patients and staff knowledgeable about services should be available 24 hours a day. This office should be responsible for establishing and maintaining a system whereby qualified sign language and oral interpreters can be obtained on short notice 24 hours a day.

II. The unit to which a deaf patient is admitted should immediately notify the designated office when a deaf patient is admitted.

III. An interpreter, if available within the hospital, should be sent to the patient immediately to consult with the patient as to the patient's preferred method of communication, which may include:

1. Use of qualified sign language and/or oral interpreter;
2. Lipreading;
3. Handwrittten notes;
4. Supplemental hearing devices, or any combination of the above.

The interpreter should give the patient notice of his/her right to a qualified sign language and/or oral interpreter to be provided by the hospital without charge to the patient, and to his/her right to a different interpreter if he/she is unable to communicate effectively with the interpreter provided.

Should no interpreter be available within the hospital the patient should be given notice of these rights in written form (at a reading level no greater than 5th grade level), and be given the option of choosing one of the above methods of communication.

IV. When an interpreter is the preferred method of communication, the interpreter assists in communications between the patient and hospital staff in all situations where effective communication is necessary to insure that the deaf patient is receiving equal services and equal opportunity to participate in and to benefit from hospital services. These situations include, but are not limited to:

1. Obtaining the patient's medical history;
2. Obtaining informed consent or permission for treatment;
3. Diagnosis of the ailment or injury;
4. Explanations of medical procedures to be used;
5. Treatment or surgery if the patient is conscious, or to determine if the patient is conscious;
6. Those times the patient is in intensive care or in the recovery room after surgery;
7. Emergency situations that arise;
8. Explanations of the medications prescribed, how and when they are to be taken, and possible side effects;
9. Assisting at the request of the doctor or other hospital staff;
10. Discharge of the patient.

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Friends or relatives of a deaf patient should not be used as interpreters unless the deaf patient specifically requests that they interpret. Deaf patients, their friends, and their families should be told that a professional interpreter will be engaged where needed for effective communication.

V. The deaf patient should be informed that another interpreter will be obtained if the patient is unable to communicate effectively with the assistance of a particular interpreter. The hospital shall obtain another interpreter if the patient indicates difficulty communicating with a particular interpreter.

VI. Any written notices of rights or services and written consent forms should be written at no greater than 5th grade reading level for deaf patients. An interpreter should be provided to assist if the deaf patient is unable to understand such written notices.

VII. A telecommunications device for the deaf (TDD) should be obtained and used for making appointments, for giving out information, and in emergency situations. Portable TDD's should be available on request for deaf inpatients.

Telephone amplifiers should be provided for hearing-impaired patients. All telephones should be compatible with hearing aids equipped with a telephone coil.

VIII. Alternative methods to auditory intercom systems, paging systems and alarm systems should be provided for hearing-impaired patients.

IX. Ongoing efforts should be made by the hospital to sensitize staff to the special needs of deaf patients.

X. Contact with deaf people in the community, organizations for and of the deaf, and community agencies serving deaf people should be maintained for assistance in developing a list of qualified interpreters and in developing a program of hospital services that is responsive to the needs of deaf patients.

GUIDELINES FOR DIRECT CARE STAFF

There are many things individual hospital staff can do to aid in communication with a deaf patient, make the patient more comfortable with the hospital environment, and thereby give better services to the patient. Common sense combined with some basic information about deafness will aid hospital staff in providing good health care to deaf patients. It is important to remember that the deaf patient is the best resource and should be consulted as to the preferred mode of communication and any problems that arise. The communication barrier between deaf and hearing people isolates deaf people and is overcome to the greatest extent possible by explaining what is happening and answering any questions the patient might have.

The importance of using a qualified interpreter to insure effective communication cannot be overemphasized. However, there may be routine situations (such as bringing dinner, checking in, taking temperatures, etc.) where an interpreter is not necessary. The following guidelines on working with deaf patients will help compensate for the absence of an interpreter when one is not present and will generally improve the quality of care provided.

I. Make added efforts in communication to insure the patient understands what is going on.

    1. Allow more time for every communication. Don't rush through what you want to say. Repeat yourself using different phrases and be sure you have been understood.
    2. Don't exaggerate your lip movements. Speak at a normal rate of speed and separate your words.
    3. Don't restrict both arms. Leave the writing free and write and sign.
    4. Make cards or posters of usual questions and responses that can be pointed to quickly.
    5. Keep paper and pen handy, but be aware of the wide range of English language fluency and writing skills.

II. Be sensitive to the visual environment of deaf patients by adjusting lighting and using visual rather than auditory cues and reassurances.

    1. Use charts, pictures, or three-dimensional models when explaining information and procedures to deaf patients.
    2. Don't take a deaf patient's glasses away, or leave a deaf patient in total darkness.
    3. Avoid having your back to a bright light when communicating, as glare makes it difficult to read signs or lips.
    4. Face the patient when speaking and don't cover your face or mouth.
    5. Keep your facial expressions pleasant and unworried. If you look like death is around the corner, the patient will be alarmed.

III. Alert all staff to the presence and needs of the deaf patient and be sensitive to those needs.

    1. *Flag* the intercom button so that workers will know the patient is deaf and requires a personal visit rather than a response over the intercom.
    2. *Flag* the patient's charts, room, and bed to alert staff to use the appropriate means of communication.

IV. Sensitivity to the special needs of people with hearing aids requires that hospital personnel:

    1. Always allow the patient to wear the hearing aid;
    2. Not shout at the patient;
    3. Make sure that the patient has fully understood what has been said.

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TIPS ON HEARING AID USE AND CARE:

1. Hearing aids make sounds louder, they do not make sounds clearer. Don't assume that a patient who wears a hearing aid will hear perfectly. The use of a hearing aid does **not** mean the patient understands speech.
2. Many people rely on hearing aids for communication and may want to wear the aid at all times including during surgery, delivery, and/or in the recovery room. Ask the patient.
3. A hearing aid user will adjust the volume of the aid for various situations. In some situations a patient may turn the hearing aid off. If adjusting the volume setting for a patient, rotate the dial slowly several times. Ask the patient to indicate when the level is comfortable.
4. Noise may be distracting or bothersome to a hearing aid user. Other noises in the room (such as a radio, television, other conversations) may be louder than your voice and may make it difficult for the patient to hear you. Eliminate or reduce extraneous sound when talking with a hearing aid user. Warn the patient who wears a hearing aid before loud sounds occur.
5. When talking to a patient who wears a hearing aid be sure your whole face is visible to the patient.
6. Keep the hearing aid available and accessible to the patient at all times.
7. During long hospital stays establish with patient and staff a place to keep the aid when not in use.
8. If necessary to remove an aid for a patient turn the aid **off** before taking the earmold out of ear. Likewise, put the earmold in ear and make sure it is comfortable before turning the aid **on**.
9. Learn how to place an earmold in ear properly. Be sure earmold is in the correct ear.
10. Check to be sure the aid is working properly before putting it on the patient.
11. Ask the patient what the controls on the hearing aid do and learn the proper settings. Check to see that the aid is set properly before putting it on the patient.
12. Hearing aids should not be exposed to temperatures above 120° nor to radiations such as x-ray or diathermy.
13. Keep the aid dry at all time.
14. Open the battery case or remove the battery at night.
15. Insert the battery by matching the + mark on the battery. (see illustration)
16. Ask the patient to keep a supply of batteries available. Store extra batteries in a cool, dry place.

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17. Remove batteries if aid will not be used for a long period of time.

18. Never wrap the cord around a body aid. Avoid twisting, knotting, chewing the cord.

19. Ask the patient to keep a spare cord available.

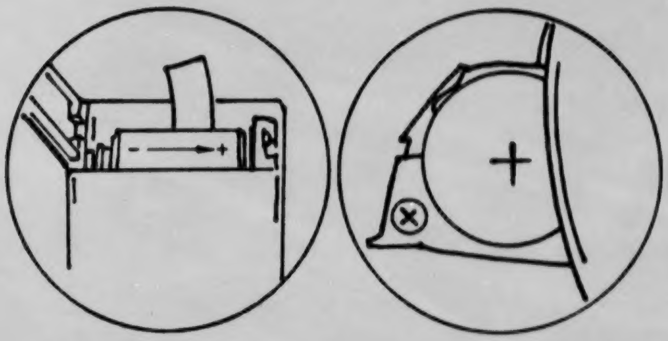
20: Avoid twisting or puncturing tubing on ear-level aids.

21. Under no circumstances should the case of the aid be opened.

22. When necessary, clean the outer case of the hearing aid with slightly dampened cloth.

23. Check earmold routinely to see that canal is free of dirt and wax.

24. Detach earmold when cleaning is necessary. Clean with mild soap and water. Never use alcohol or cleaning fluid. Make sure earmold is dry before reattaching it to the aid.



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CONSIDERATIONS FOR OFFICE MANAGEMENT OF DEAF PATIENTS

General Communication Tips

1. When communicating with a deaf patient be sure the patient can see your face and body.

2. Get the patient's attention before you begin talking. It may be necessary to gently touch the patient. Receptionists should go into the waiting room to summon deaf patients personally rather than calling their names.

3. Arrange lighting so that it is on your face and body, on the interpreter if one is present, and on any written messages or pictures you are using.

4. Make a conscious effort to use gestures and facial expressions with deaf patients. Match gestures and facial expressions to the message you are trying to convey.

5. Pictures and models can be an effective communication tool for you and your deaf patient. Use pictures and models that relate to the message you are trying to convey or draw simple pictures and diagrams.

6. Allow the deaf patient to select the preferred mode of communication. Be sure you understand the method of communication the patient requires and be prepared to supply that method.

7. Deaf patients respond to visual information. The frustrations of busy or hurried personnel and worried facial expressions may create undue fear, anxiety or other negative reactions that can interfere with adequate communication.

8. Be sure you are understood and tell the patient if you do not understand.

Tips on Talking With Deaf Patients

1. Speak clearly, only slightly slow the speed of your speech. Any exaggeration distorts visible pattern.

2. Do not shout. Shouting distorts the lip movements and the sound of your voice.

3. Rephrase and repeat. Each time you repeat or substitute other words you have another chance at succeeding in communication.

4. Keep pad and pencil within reach of patient at all times.

5. When interpreting the deaf person's written messages to you look for key words and concepts if the grammatical structure is not what you expect.

6. Rephrase, repeat and ask questions to be sure the patient understands your message and you understand the patient's message.

7. If you cannot understand the written message from a patient contact a family member or interpreter.

Interpreters

1. When an interpreter is the preferred mode of communication, the interpreter should assist in all situations where effective communication is crucial.

2. Routine situations may not require an interpreter but in situations such as obtaining informed consent or permission for treatment, explanations of medication or procedures, and taking a case history require an interpreter.

3. Family or friends may be helpful in some situations but should not be expected to serve as interpreter.

4. Talk directly to the patient not to the interpreter.

5. You should define terms and provide explanations if the patient does not understand, not the interpreter.

6. The interpreter should interpret everything said as accurately as possible including side comments and comments between dental staff.

Telephone Use

1. Telecommunications devices (TDD's) make telephone use possible for deaf people. If your patient has a TDD indicate that on the record and record the telephone number.

2. If your patient does not have a TDD, ask for the name and telephone number of a hearing family member or friend.

3. Many cities have answering services for deaf citizens. Ask your patient if such a service is available in your community. If so, you may contact the service by telephone and the service operator will in turn contact your patient by TDD.

4. You may find purchase of a TDD for your office beneficial to both you and your patient.

General Management Tips

1. A team approach involving the dental staff, parents, teachers, counselors, public health nurse, social workers, the patient and/or others may be required more frequently with deaf patients to insure continuity of care.

2. To obtain an accurate understanding of the patient's health history, the dental staff may need to consult professionals, family members as well as the patient.

3. Schedule adequate time to establish rapport with the deaf patient and to determine preferred communication mode.

4. Explain unexpected long waits to deaf patients to ease the tedium of the wait and to assure you have not forgotten them.

5. Explain procedures and alternatives clearly. Schedule appointments to insure there is adequate time for explanations.

6. Explain referrals clearly and indicate reasons.

7. Explain medications and/or prescriptions to deaf patients and indicate possible side effects.

8. Demonstration of procedures, instruments and equipment may be helpful for providing explanation and easing anxiety.

9. Explain the concept of local anesthesia prior to beginning treatment. Explain this procedure by telling the patient you are putting the teeth and gums to sleep and that the patient will feel no pain while the dentist works. Establish a system for the patient to indicate to you if a procedure is painful.

10. Allow patients to wear hearing aids and glasses during all procedures, including surgery. If it is absolutely necessary to remove glasses, keep them within reach of the patient. If the patient wears a hearing aid, cue the patient prior to sounds such as the drill.

11. Because of the prevalence of poor oral hygiene among deaf children, preventive dentistry should be emphasized. Oral hygiene training will require more demonstration and modeling than with other patients.

12. Some patients are hesitant to report a hearing loss, especially adults and older people who are losing their hearing. Learn the symptoms of hearing impairment so that you can detect an unreported hearing loss and make accommodations for communication.

The Deaf Child

1. Parents of the deaf child may be helpful in conveying information to the deaf child, monitoring the child's home oral health care, providing information on the child's possible behavior or reaction, and in establishing confidence. Watch the parent for tips on communicating with the deaf child.

2. Some parents magnify the implications of deafness and overprotect their deaf children. Many do not communicate well with their deaf child. Parents should not be used as interpreters if they talk for their deaf child or make the child anxious. A sibling, teacher, or interpreter may be more appropriate.

3. Prior to the first appointment with a deaf child (a) obtain a complete medical history, (b) meet with a parent to explain what will happen and ask the parent for the visit using pictures and other communication aids. Provide illustrated brochures and other materials for the parent.

4. Schedule the appointment so that the deaf child spends as little time in the waiting room as possible. It may be helpful to allow the deaf child to observe well behaved siblings or friends during dental examinations.

5. Demonstrate procedures and equipment on yourself, an assistant or parent.

6. Allow a parent, sibling or friend to accompany the patient in the operatory. Position the child so the person accompanying him can be seen.

7. Talk directly to the patient even if the child watches the interpreter or parent most of the time.

8. Remember the deaf child is a child first. Appropriate modifications in delivery of dental services should be made according to the age of the child just as with children who are not deaf. Although communication may be impaired other developmental milestones should be normal for the deaf child.

Communicating with a Visually Impaired Person

Most people find it obvious that a disability which affects speech or hearing will interfere seriously with effective communication. The effect of a visual impairment, however, may not be so obvious. Harold Krents is an attorney who was blinded at age 9. Krents, who was the inspiration for the play and film, *Butterflies Are Free*, has found that some people speak to blind persons as if they were unable to speak or hear normally. People may exaggerate their pronunciation, shout, or whisper in front of a blind person.

TIPS

1. Introduce a blind person just as you would anyone else. It is inappropriate and also unnecessary to say, for example, "This is Jim Jones. Jim is blind."
2. Use words such as "look" and "see" comfortably. These words are a part of English vocabulary and it is unnatural to avoid using them.
3. When approaching a person with a visual handicap, always state your name. Unless he or she knows you well, do not expect a blind person to be able to identify you by your voice, especially in noisy surroundings.
4. Let the person with a visual problem know when you are about to leave. Do not walk away without saying anything.
5. If the person you are talking to has some limited vision, do not stand with your back to a window. The glare may be uncomfortable and cause eye fatigue for the person who has some vision.
6. A visually handicapped person may need verbal cues to help compensate for the loss of information usually obtained from facial expressions, gestures, and body movements. For example, persons with normal sight know when a question is directed toward them because the speaker looks at them. A blind person may not realize that a question is meant for him or her unless you preface it with his or her name ("Bob, what is your address?").
7. We normally judge whether a person is paying attention by the amount of eye contact used. When speaking to a person with a visual handicap, repeat his or her name often and ask questions to be sure he or she is "with" you.
8. Vision impairment does not necessarily mean a lack of intelligence. Be cautious in making assumptions and evaluations.

Communicating with a Physically Handicapped Person

The majority of people who have motor damage, especially those with cerebral palsy, have mild to moderate communication difficulties. Damage to the central nervous system may interfere with the production of speech sounds and with the rhythm and rate of speech. The most common characteristics of motor speech disorders are imprecise production of consonant sounds, slow effortful speech, and difficulty in control of pitch and loudness. When muscle function is impaired, speech may be accompanied by facial distortions, drooling, and random body movements.

These behaviors often distract listeners and make them feel uncomfortable; you may have to make a conscious effort to pay attention to what the speaker is saying. Also, the physical tension associated with speaking and the difficulty in being understood often discourage handicapped people from attempting to communicate; to overcome this reluctance, you need to be accepting, relaxed, and interested.

Severely physically handicapped people may not be able to communicate effectively with speech. As a supplement to or substitute for speech, these people may use one of the more than one hundred existing nonspeech systems. These nonspeech modes include sign language, pantomime, Morse code, communication boards (symbols printed on paper, cardboard, plastic, Masonite, or plywood), manipulatable symbols, drawn or written symbols, machine-generated speech, braille, and adapted electric typewriters.

The effect of the motor disability itself may be increased by hearing loss, mental retardation, defective oral sensation, seizures, perseveration, hyperactivity, distractibility, or psychological problems.

TIPS

1. When you meet a person with an unfamiliar disability, you may have to consciously avoid staring. At the same time, it is a mistake to avoid eye contact because you feel uncomfortable. Instead, look at the person in the same way you look at a nondisabled person, with eye contact and a smile or greeting.

2. Speech intelligibility of a person with a motor speech disorder will often improve after you become accustomed to the distorted speech pattern. You can obtain a good sample of the person's speech by asking a question which requires a lengthy answer (for example, "What do you enjoy doing?") or by having him or her read aloud.

3. Allow a long response time from someone who has a motor speech disorder. A physical disability may increase the time needed to initiate speech.

4. Do not be offended if a person who speaks with some physical tension seems reluctant to converse. This may be because of the great effort the person expends in order to speak. Encourage the person to speak and create an accepting atmosphere by using eye contact, smiling, leaning forward, and nodding.

5. If the person uses a nonspeech communication system, become acquainted with the way the system works and benefits. If you have reservations about nonvocal communication, you are likely to convey this attitude to the handicapped person. If, on the other hand, you are willing to accept the nonvocal method as a functional means of communicating, you will convey your respect to your protege or client. This can only enhance your relationship with him or her.

6. Respect the personal space of a person with a physical handicap. You must be close enough to be easily seen and heard, but realize that a person with a physical handicap may not be able to protect his or her personal space. Personal space includes any equipment an individual uses; leaning on a person's wheelchair, for example, is rude and may even seem threatening.

7. If the handicapped person must remain seated, try to sit also so that you can maintain the same eye level. Even if you maintain a comfortable distance, you may still appear to be threatening and dominant if you stand. This is the teacher-pupil or boss-employee position.

8. Be sensitive about touching someone with a neurological handicap. A pat on the back or a hug is a pleasant, positive experience for most people, but for someone with neurological damage, another person's touch may be irritating or even frightening. This does not mean that you should avoid touching completely; just move slowly so you don't startle the person and use firm pressure (a light touch may tickle).

9. To keep the attention of a hyperactive or distractible person, call the person's name frequently or touch him or her on the arm or shoulder. If the person cannot focus attention on one activity, limit the number of distractions, such as unnecessary furniture and equipment, bright, patterned wallpaper or carpet, or an uncovered window.

10. If you note signs of fatigue, anxiety, irritability, or disinterest, change activities, slow down, make the task simpler, or take a break. Perseveration (the continued repetition of a response when it is no longer appropriate) is likely to occur when an individual is tired, when situations change rapidly, or when a task is too difficult.

11. Physical handicaps and speech disorders do not mean a lack of intelligence. Focus on the person's abilities, not disabilities.

Session Three

Resources

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TIPS FOR THE ALLIED HEALTH PROFESSIONAL INTERACTING WITH HANDICAPPED CHILDREN & YOUTH

The following pages contain some tips which Allied Health professionals may find useful when they interact with a child/youth with special needs. Suggestions on this page are general and apply to most children/youth with handicapping conditions. Also included in these pages are ideas intended for children/youth with mild handicaps (learning disabilities and mild retardation), communication disorders, hearing impairments, visual impairments, and orthopedic impairments.

General Tips:

- Relate to the child, not just the child's label.
- Try actively to understand how the child feels.
- Accept the child and see him/her as a learner.
- Help the child feel accepted. Once the child feels accepted, he/she will usually your expectations if they are within his ability.
- Realize that your acceptance is a prerequisite to child's acceptance of self.
- Promote friendships between the exceptional child and other children in the health-care facility.
- Expect the child to meet established rules.
- Realize that poor behavior may be caused by boredom, or an inability to respond because of the mode of presentation. Maintain challenges and responsibilities.
- Be consistent; make needed modifications gradually.
- Include the child in conversations; do not shelter the child with a handicap.

TIPS FOR THE ALLIED HEALTH PROFESSIONAL INTERACTING WITH CHILDREN/YOUTH WHO ARE MILDLY HANDICAPPED

Children and youth with learning disabilities may have processing difficulties or mild forms of any sensory impairments. Those professionals who work with these children may find it helpful to skim other pages for more helpful hints.

A. Presenting Information

- Focus on the child's strengths.
- Present information in small sequential steps.
- Use several short learning periods; this is more effective than having one long period.
- Present the same concepts using a variety of materials and approaches.
- Help the child recognize how he/she can use the learned shells in his daily life.
- Use a multi-modality approach whenever possible.
- Include realistic practice; students learn by doing rather than reading or hearing about it.
- Present tasks in a clear, concise manner to increase the child's success potential.

B. Other Considerations

- Use concrete objects whenever possible to illustrate abstractions.
- Practice on realistic materials so skills are more easily transferred. For example, real money is more effective teaching tool than play money.
- Increase the use of tactile and manipulative materials.
- Present materials at child's readiness levels, while respecting his/her chronological age.
- Look for high-interest low-level materials.
- Some children may have difficulties with distractability. Provide a small cubicle, or separate chair behind a screen, to temporarily separate the child from the activities of the surrounding area.

TIPS FOR THE ALLIED HEALTH PROFESSIONAL WORKING WITH CHILDREN/YOUTH WHO ARE HEARING IMPAIRED

A. Environmental Considerations:

- Arrange the seating so that the child can sit near you and observe your face, as well as others in the room.

- Be aware that gesturing and facial expressions are important cues which help the hearing impaired child's understanding.

- Realize that the child needs to see your full unobstructed face to gain cues. Long hair or a mustache may obstruct the ability to see your face and lip formations fully.

- Allow the child to move around to see the speaker.

- Have the child sit with his/her back to the light so the light falls on your face, or on the material the child must focus on.

Children/Youth with Hearing Aids:

- If the child wears a hearing aid, consult with the parents, teacher of the hearing impaired, or an audiologist for specific information on the operation of the aid. Unless the child checks his/her hearing aid, it would be helpful for you to know how to check the aid to see if it were working properly. Specifically:

    1. Check to see if the aid is on.
    2. Check connecting plug for firm connection.
    3. Check for frayed wires.
    4. Have spare batteries and know how to change them.
    5. Check to ensure earmold is properly inserted.

- A Child with a hearing aid should be 4 - 10 feet away from the speaker. Remember to use a normal voice; exaggerated speech distorts sounds and lip movements. Speaking too slowly is as ineffective as speaking too fast.

- Aids amplify all sounds including instructional and environmental sounds, such as feet shuffling, paper crumpling, air conditioning, etc.

B. Other Considerations:

- Listening skills must be encouraged to help the child maximize any residual hearing; encourage the use of any hearing the child does have. An audiologist can help here.

- Listening is hard work; provide a variety of activities balancing those that require concentrated attention and that are more natural and thus relaxing for the child.

- If a word has several meanings, explain them. Words like pail or plain, if lip read, look like pale and plane -- the child needs to know all meanings so comprehension is increased and confusion decreased.

C. Materials and Media Considerations:

- Use a lot of visuals -- pictures, models, posters, manipulatives, etc., to supplement your verbal presentations; the old adage a picture is worth a 1,000 words is true here.

- When using pictures and models be sure to hold them to the side of your face, not covering your face. Holding them over your chest tends to make you want to look down and talk, thus obscuring your lips from the child's view.

- When presenting instructions, have them available in print as well as giving them verbally.

D. Presentation Considerations:

- Organize your presentations into sequential steps. Indicate clearly when you move from step to step.

- If you need to repeat something, try rephrasing it to give more cues. Don't just repeat and repeat the same thing.

- Periodically summarize what has gone on before proceeding. Ask for confirmation that concepts are understood before going on.

- Make transitions from one topic to another very obvious. Use body movements, and visually hold up the object you are about to discuss.

TIPS FOR THE ALLIED HEALTH PROFESSIONAL WORKING WITH CHILDREN/YOUTH WHO ARE VISUALLY IMPAIRED

A. Environmental Considerations:

- Seat the child in clear view of the person speaking.
- Seat the child with his/her back to the light.
- If the room arrangement is changed, inform the child and let him/her explore where and how these changes were made.
- Keep supplies in the same, predetermined place. This will allow the child greater independence in locating the materials needed.
- Be sure the child knows about the location of any breakable, or potentially harmful objects.
- Half-open or swinging doors can be potentially dangerous; have doors either open or closed.
- Tell the child when you are leaving or entering the room.

B. Other Considerations:

- Most partially sighted children can learn to use their residual sight; encourage the child to do so.
- When written directions are given, read them aloud giving auditory information.
- Whenever possible, have information on tape -- these can be prepared by you, an aid, or a volunteer.
- Using a residual sight may make the child tire easily, as it is hard concentrated work. Plan varied activities so as not to fatigue the child with one type of visual task.
- Assist the child in actively developing listening skills.

C. Developing Social Skills:

- Habits such as rocking back and forth, head rolling, or staring at bright lights may have developed because of a need for a self-stimulation. To decrease this behavior, it may be helpful to keep the child involved in interesting, manipulative-type tasks. Also, do not hesitate to quietly remind the child of such habits.

D. Material Considerations:

- Use concrete objects and manipulatives to give tactile cues the child can learn from.

- Become familiar with materials such as large print books and cassette tapes available from the State library, and your Special Education Regional Resource Center (SERRC). Also, pamphlets containing useful information can be obtained from your local Bureau of Services for the Blind (BSB).

A. Environmental Considerations:

- Allow room for movement -- increase aisles to 60" and more for turning corners.
- Identify or help plan for strategically located ramps, bathrooms, drinking fountains and curb grading to increase the child's mobility in and around your facility.
- Be sure there is adequate maneuvering space next to a door.
- Provide ample space near a child's chair or table to store crutches and any other adaptive equipment.
- Doors should not require more than approximately 6-8 lbs. of pressure to open (even less for smaller, younger children using wheelchairs). If such doors are a problem for the child, arrange for assistance.

B. Other Considerations:

- Make materials available on a level which is comfortable for the child in a wheelchair to reach them -- on the first shelf rather than on counter tops, etc.
- Encourage development of writing skills. Slow and illegible writing should be understood as a motor control problem rather than as an intellectual deficit.
- Let the child take an active role in demonstrating and explaining any adaptive equipment he/she may use.
- As with any child, be sure to provide successful experiences for this child.

C. Medical Considerations:

- Maintain open communication between the parents and medical personnel. This can be very helpful in understanding the medical needs of a child.

- Know any medications taken by the child, and any possible side effects that could affect behavior or performance. For example, certain medications may cause tiredness or frequent urination.

- Be aware of the physical stamina limitations imposed on a child by a particular disabling condition. Such a child's schedule might alternate between active stressful activities and more passive, relaxing tasks.

- Be aware that it needs more physical energy for the disabled child to be mobile, whether that child is using crutches, braces, or a wheelchair.

- Some children may be on a specific schedule for using restroom facilities. Encourage them to independently meet their own needs here (as opposed to being reminded of time schedules, etc.).

- Understand that people who sits in wheelchairs for hours at a time may develop problems with circulation. To prevent this, they will shift their weight frequently. This is not fidgeting or restlessness.

- If a child is known to have any form of epilepsy, be aware of how to deal with possible seizures. The child's parents, physician, nurse, or local epilepsy foundation can all be helpful sources of information. Overall, the most important thing you can do during a seizure is to be prepared to remain calm, and to explain to others present about the occurence in a matter-of-fact way.

- Regular exercise and participation in active programs is good for all children, including epileptic, orthopedically handicapped, and other disabled children.

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D. Considerations for Children with Motor Coordination Problems:

- Provide adequate time to complete a task.

- Be aware that some children may have difficulty in speaking clearly. Your patience is needed here, to be understanding and to become familiar with the child's words.

- If a spastic or jerking movements are exhibited, understand that the child is not acting out or "behaving strangely" intentionally. These involuntary motions cannot be controlled by the child. Familiarity here will help everyone involved to feel more comfortable.

TIPS FOR THE ALLIED HEALTH PROFESSIONAL WORKING WITH CHILDREN/YOUTH WHO HAVE LEARNING DISABILITIES

A. Presenting Information:

- Break tasks into very short tasks.
- Give verbal as well as written directions whenever possible.
- Give them only one (or few) questions at a time during testing.
- Include only that material which is absolutely necessary.
- Establish a few realistic goals.
- Keep child's area free from all material except what he/she is working with.
- Keep the number of practice items on any skill to a minimum.
- Give the child a longer time than other children to complete tasks.
- Alternate tasks that are difficult and those that are more relaxing.
- Establish a specific schedule so the child knows what to expect.
- Keep work periods short; gradually lengthen them as child begins to cope.
- Alternate quiet and active time; have short periods of each.
- Make movement as purposeful as possible.
- Make certain the child understands directions of assignments, repeating important directions.
- Change activities before the child's attention is gone; watch for early signs of attention loss.
- Provide options for obtaining and reporting information -- tapes, interviews, reading, experience, making something, etc.

1. Listens to understand what is meant, not to get ready to reply, contradict, or refute. This is extremely important as a general attitude.

2. Knows that what is meant involves more than the dictionary meaning of the words that are used. It involves, among other things, the tone of the voice, the facial expressions, and overall behavior of the speaker.

3. Observes all this and is careful not to interpret too quickly. Looks for clues as to what the other person is trying to say, putting one's self (as best as possible) in the speaker's shoes, seeing the world as the speaker sees it, accepting the speaker's feelings as facts that have to be taken into account--whether the listener shares them or not.

4. Puts aside own views and opinions for the time being. Realizes that one cannot listen to one's self inwardly and at the same time listen outwardly to the speaker. Is careful not to "jam" the receiving set.

5. Controls impatience knowing that listening is faster than talking. The average person speaks about 125 words a minute, but can listen to about 400 words a minute. The effective listener does not jump ahead of the speaker, but gives the person time to tell his/her story. What the speaker will say next may not be what the listener anticipates.

6. Does not prepare an answer while listening. Wants to get the whole message before deciding what to say in turn. The last sentence of the speaker may give a new slant to what was said before.

7. Physically shows interest and alertness. This stimulates the speaker and improves performance.

8. Does not interrupt. When asking questions, the purpose is to secure more information, not to trap the speaker or force the speaker into a corner.

9. Expects the speaker's language to differ from the way the listener would say the "same thing." Does not quibble about words but tries to get at what is meant.

10. The purpose is the opposite of a debater's. Looks for areas of agreement, not for weak spots to attack and blast with an artillery of counter-arguments.

11. Listens to all participants, not only to those who are on his/her side.

12. In a particularly difficult discussion the listener may, before giving an answer, sum up what he/she understands was meant by the speaker, clearing up contested points before attempting to proceed.

BRIDGING THE PARENT PROFESSIONAL COMMUNICATION GAP*

> "Whenever I'm meeting with professionals I usually feel so frustrated, angry, guilty and helpless."

Did you know that when professionals have meetings with parents that they feel "frustrated, angry, guilty, and helpless"? This was documented at the 1979 IOWA ACLD CONFERENCE WORKSHOP where a group of approximately ten parents and fifteen professionals were separated (with all the parents together, and all the professionals together) into two groups and were asked separately to list their feelings during meetings with parents (in the professional group) and with professionals (in the parent group).

HERE ARE THE LISTS EACH GROUP CAME UP WITH: (in the order presented)

PARENT GROUP LIST: "When I'm meeting with professionals I feel ..."

a desire for honesty
run around
don't know too damn much
frustrated by jargon
anger
disgust
disappointed
defeated
guilt, guilt, guilt
overwhelmed
good
unsuccessful
trustful
respectful
sympathy
defensive
threatened

"I wish professionals were more ..."

helpful
child oriented
concerned
knowledgeable
receptive to profession upgrading
humanistic
understanding
free to be open

---

* Adapted from "How To Get Services by Being Assertive" by the Coordinating Council for Handicapped Children.

.../2

"I like it when professionals ..."

contact/communicate with me
listen to me
come with positive information
show respect for students
become involved in support groups
respect the knowledge of parents
individualize for students
share information
share professional knowledge
treat parents as equal

PROFESSIONAL GROUP LIST

"When I'm meeting with parents I feel ..."

frustrated
professional liability
parents don't care
parents not very informed
uptight
threatened
insecure
pressured
patronized
tired, burned out
tense
upset
unsure
incapable of dealing with parents
unprepared indignant
put down
successful
organized
confident
satisfied
knowledgeable
helpful
appreciative
fulfilled
accomplished
good about myself
needed
burdened with red tape

"I wish parents were more ..."

better listeners
informed

.../3

"I wish parents were more ..." (cont'd)

assertive
interested
less intimidated
reliable
initiating in dealing with problems
responsible
caring
involved
supportive
objective
better models
sensitive

"I like it when parents ..."

ARE PERFECT
attend conferences, staffings ...
follow through with suggestions
both attend meetings
see progress
provide feedback regarding the child's "performance"
are supportive of special services
are open with their communication
put their child's education first
show initiative in finding out what their child does in school
remember me at Christmas time
are honest
are objective
understanding of professional perspectives
are open minded

If you remember that professionals and parents are experiencing the same feelings when you are meeting, and you both are "frustrated, uptight insecure, threatened, tense, upset, unprepared, put down, burdened with red tape ..." you can meet as partners, involved in the same meeting, sharing the same feelings, the same frustrations, the same fears.

Remember, when you are feeling frustrated, the other person too may also be frustrated; when you are feeling angry, that he/she too may be angry; when you are feeling afraid, that he/she too may also be afraid; when you are feeling helpless, that he/she too, may be feeling helpless. A real partnership can develop between you if you can share your feelings with each other.

COLLABORATIVE PROBLEM SOLVING PLANNING FOR CHILDREN WITH DEVELOPMENTAL PROBLEMS

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COLLABORATIVE PROBLEM SOLVING PLANNING FOR CHILDREN WITH DEVELOPMENTAL PROBLEMS

Mark N. Ozer, M.D.

Introduction

Recent federal legislation has mandated that the assessment of children with developmental problems lead to operational plans on an ongoing basis including goals, means and time for review. It is no longer sufficient for the assessment process to lead only to the determination of an administrative category such as mental retardation, emotional disturbance, learning disabilities and so forth. This same legislation has also mandated parental involvement in planning for the special needs of their children. The regulations implementing these laws have established procedures for parental approval of any plans and have protected the rights for appeal of decisions made by educational authorities.

This paper will describe an assessment process designed to carry out both the spirit and the letter of these legal requirements. It is based upon the premise that resources within the educational system are always limited; that the treatment of children with developmental problems must be done with the involvement of those who remain primarily responsible; and that the assessment itself, if properly conceived, can increase the competence and confidence of parents in caring for their children. This paper will also describe how allied health persons on planning teams may serve as resources in carrying out these approaches.

The Planning Process

If the assessment is to lead to an operational plan, it is necessary to reconsider both the type of data collected and how such data may be collected with the involvement of the parent. It is helpful to think of the assessment process as a series of questions leading eventually to the final question: WHAT ARE THE GOALS AND THE MEANS FOR CARRYING THEM OUT? What are the questions traditionally asked and what changes should be made?

The first question traditionally asked seeks to define the problem: WHAT IS NOT GOING WELL? Much of the effort of the assessment team is devoted to exploring the child's function by various tests to determine areas of both "strength" and "weakness." The areas determined to be dysfunctional then determine the goals for the remediation plan. Much, if not all,of this exploration is done by professional staff using standardized tests. Such testing has been criticized in terms of both the content of the tests and the process by which they are administered (Bersoff, 1973). The performance of a child on such tests relates only to a limited degree to performance on actual tasks required in the home and school. It is not uncommon for artefacts of the testing procedure to lead to the determination of both "underachievement" or "overachievement" when performance is compared to the classroom. It is the performance of the child in the context of the classroom tasks and conditions that is the most effective predictor of future performance (Keogh and Smith, 1970).

It would therefore be appropriate to involve the parent from the start of the assessment in helping to define the problem along with the professional staff. It is the statement of the problem by all those concerned that insures collaboration in eventual remediation.

Although the collection of data by the testers seeks to define both strengths and weaknesses, it is suggested that the question as to strengths be made even more focussed. It has been found helpful, once a problem area has been identified, to ask: IN AN AREA OF CONCERN, WHAT HAS THE CHILD BEEN ABLE TO DO SUCCESSFULLY? At least three postive situations are to be described. If, for example, a problem has been identified in the area of following oral directions; then the next question would be: At what times during the past few days or hours have you found it possible to have the child follow directions?

There are several purposes for this new more highly focussed question as to "strengths." In light of the ultimate plan to be generated, it is useful to define the base from which new goals are to be set. It is helpful to know as specifically as possible what the child is able to do at the present time to set appropriate goals for the future. This new question has still another purpose. It is designed to change the perception of those involved in the planning. Any question also imparts a message. In this instance, the message being conveyed is that this child may well have islands of "wellness" even in those areas considered to be "unwell." It is important, in light of the ultimate goal of committment to carry out the plan, to increase the awareness of those involved with the child of the fact that there have been situations when even this problem has been solved. It would be ultimately necessary, in order for the plan to be successful, for those responsible for the child to give their selective attention to those albeit infrequent occurrences if such occurrences are to increase in frequency. The very process of assessment helps to bring such awareness about.

The search for three such episodes of success has the purpose of making the change in perception more likely. If the person providing the data has merely identified one such occurrence of successful listening, it is indeed a rare event. Even if two such occurrences could be documented, it is rather infrequent. However, if at least three episodes could be documented, it begins to seem more likely that one may indeed perceive the child as doing what one wishes to see happen more often. One may have hope for the future. The goals one may set may indeed be possible.

Still another purpose is being served by this new question as to successes in the area of concern. The data generated by this question now provides the context for exploring the next new question in this planning sequence:
AT A TIME WHEN THINGS HAVE GONE WELL, WHAT DID YOU DO TO MAKE IT POSSIBLE?
The situation in which the ideas as to what worked are to be generated is one within the recent memory of the person. Attempts are made for that memory to be as vivid as possible in terms of details such as where? when? who? The feeling tone of that situation is evoked as well as ideas generated. For example, the person recalls the child staying in the front yard of the house yesterday after school as an instance when he followed directions. What worked, she thought, was "asking him to repeat what he was to do, showing him the boundaries of the yard and promising him an ice cream cone." It is not suggested that these ideas are unusual. It is their simplicity and relation to the person's own experience that would make them compatible with future use in bringing about the accomplishment of the goals for the future. The answers to the question as to means ultimately sought at the end of the assessment thus come from what may have worked in the past.

Asking this question as to what worked also imparts an important message. The message being conveyed is that those involved with the child have data that would be crucial for the future. Such data are quite different in kind from the traditional data as to the present state of the child in terms of strengths and weaknesses. The question asks for what was done to bring about successes. The data are not about status but of change, of the conditions for change and growth.

The message is also designed to change the perception of those answering. Much energy is traditionally devoted to determining what may have been the cause of the difficulties being seen at this time with the child. Far more useful at the time of assessment would be energy devoted to exploring what might be means by which the problem might be solved. The search for three ideas in answer to this question as to what worked leads to an awareness that there are indeed things that work and have worked in the past; and that the persons involved have been themselves responsible for setting up the conditions.

Now having explored these two new questions, those involved in the planning can more effectively address the questions leading directly to the plan for the future. WHAT GOALS SHOULD BE SET? WHAT WOULD WORK TO ACCOMPLISH THEM?

In addition to new kinds of data, the assessment process in this new model cannot be effective without the awareness that the data are to be generated by the professional together with those who are the primary participants in the child's life. It is they who must become more aware of their own skills. The very process of assessment can bring about such awareness if properly conceived in terms of the data sought. When viewed as an ongoing process, the primary participants become increasingly aware of their own concerns, their own successes their own means for bringing about such successes and their own goals. (Ozer, 1980).

Role of the Allied Health Professional

The awareness on the part of the allied health professional of this problem solving planning in collaboration with the parent can bring several advantages to the entire effort of the planning team. As an independent professional; particularly in the fields of speech and language, occupational therapy and physical therapy, the individual contributes his own assessment to the total done by the entire team. In all these fields it is crucial to use this model of involving the parent who remains ultimately the primary treatment agent. Collaboration in assessment and planning is required for good therapy.

The use by the allied health professional of this approach has advantages for the activities of the other members of the team as well. In the course of interacting with the professional in this way, the parent has been prepared to provide data that could be of aid in other areas of function. Particularly relevant has been the development in the parent of greater awareness of ideas that have been helpful in solving problems in the child's development. Such data generally have relevance to a number of functional areas different from the situations in which they were first elicited. Ideas that have worked in one context frequently have application in others. The ideas that worked in relation to the child staying in the front yard in the example given earlier would of course work in other situations.

The activities carried out in this model with the parent have still another possible advantage for the planning team. Not only has the parent been prepared to contribute ideas but the form of the interaction in this collaborative assessment process has served to enhance the self-confidence of the parent and could enable her to function more effectively as a case manager.

Conclusion

The assessment procedure has been reconsidered in terms of its goals of developing operational plans with the collaboration of the parent. Changes were described in the type of data sought. Far greater emphasis should be placed on data concerning what has been accomplished particularly in the areas of greatest concern. Data should also be collected about the means by which such successes may have occurred. The ideas that have worked have general applicability and can be used in the plans for the future. The form of the interaction in which the data are sought must also be reconsidered. Questions are asked rather than directions given. Allied health professionalscarrying out the activities outlined in this model contribute to their own professional effectiveness and of the entire team in the course of enhancing the competence and confidence of the parent.

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CHAPTER V

ASSESSING PARENTAL CAPABILITIES

Family relations and child-rearing practices are topics of continuous concern in most communities. What does it take to be a good parent? How can I make my child behave? Am I doing the right thing when I praise or punish my child? Such questions naturally arise in the minds of parents. The steady flow of books, magazine articles, lectures, movies and television soap operas concerned with family life and child-rearing testifies to the central importance of such reexamination to our society.

Acceptable family patterns and child-rearing practices undergo continuous refinement as society changes. Transmitting the primary values, skills and other personality characteristics from one generation to the next is the key to a society's survival. Granted that biological as well as social factors enter into the development of an individual's personality, certain shared attitudes, beliefs and values within the culture provide a common basis for socialization of a child.

These implicit attitudes, beliefs and values constitute sociocultural premises that fundamentally determine shared personality characteristics within a given culture. Cultures differ in ways that are important for parenting as well as child development. The physician who is sensitive to, and respects, these differences will have a far greater chance to influence parenting. He will even be forgiven cross-cultural mistakes if families sense he has such an attitude.

Most mothers and fathers are called upon to adjust their parenting approaches as their children pass through successive stages of development, because parenting skills which may be appropriate to the child's needs at one stage may be inappropriate at another. For this reason, parents often find it easier to rear children in one stage of development than another. Some are more comfortable with infants, for example; others with older children. Different parents respond differently to different children, in a reciprocal fashion. "Parent development" and "family development" are valuable concepts for understanding family dynamics at any given point in time (See Table II).

Parental attitudes also are an important influence, perhaps even more important for the child's personality development than the particular child-rearing techniques the parents use. In fact, the parents' underlying attitudes may influence their choice of specific child-rearing practices.

There are few accepted objective ways of measuring the interrelated factors of parental attitudes, behavior and child-rearing practices that we

From: The Physician and Mental Health of the Child, American
Medical Association, 1979.

Table II

CHILD DEVELOPMENT, PARENT DEVELOPMENT AND FAMILY DEVELOPMENT*

Child's Developmental Stages	Individual Developmental Tasks	Parent Development	Family Development
			The marriage
Infant	Trust	Learning the cues	The birth of the first child and subsequent child bearing
Toddler	Autonomy	Learning to accept growth and development	Redefinition of roles with the birth of each child
Pre-school	Initiative	Learning to separate	Individuation of family members
School age	Industry	Learning to accept rejection, without deserting (permitting independence)	
Adolescence	Identity	Learning to build a new life	The actual departure of the child
	Intimacy		The integration of loss

*Based on Prugh's comparison[1]

call "parental skills." Nevertheless we can postulate, as ideal, certain attributes or goals:

1. The ability to provide a model for mutual respect, which can be characterized as a climate of openness within the family. This implies recognition of the importance of the child's feelings and views, even though parents maintain responsibility for making final decisions based on the needs of the family as a whole.
2. Flexibility for modifying parenting roles with each new developmental stage, which includes sensitivity to the child's changing feelings, attitudes, abilities and needs, as well as an awareness of changes associated with parental and family development.
3. The capacity to nurture. An infant's intellectual and social development during the first two years of life is facilitated if his mother provides varied stimulation, shows affection, and responds fairly quickly and consistently to his signals. The child also should be allowed "to be" and "to feel."
4. The ability to set limits. Proper structure and discipline should be provided to accord with acceptable behavior within the family and in the outside world. A "vicious cycle" develops in certain families—the child misbehaves, the parent punishes, and the punishment only stimulates the child to added misbehavior. Families caught up in such a cycle can, if they wish, be trained to interrupt it and to substitute a pattern of family functioning that is increasingly tolerable to both parents and children.

   The most effective parent is one who combines affection with strict control and joint discussion of family-related issues. Neither the parent who is affectionate and permissive nor the parent who is cold and authoritarian is as effective, when effectiveness is measured by a child's later competence in dealing with his environment away from home.
5. The ability to allow independence, which means to encourage each family member to branch out and satisfy needs outside the family system. Such encouragement, however, should be related to parental insistence that the child assume developmentally appropriate responsibilities.
6. The faculty of parents to recognize that what they *do* is more important than what they *say*, and to understand that congruence between verbal and nonverbal messages is important.
7. The capability of each parent to commit himself or herself to a marital relationship where each gives the other permission to express and satisfy needs in an acceptable manner.
8. The ability to relax and be comfortable in the parenting role, which is contingent not only upon accepting one's limitations in all of the above areas, but also upon being optimistic about building on individual and mutual strengths.

In assessing parental skills the physician should, at the outset, be aware of conditions and situations, usually historical, that are conducive to high risks in parent-infant relationships. The following list contains certain clinical clues, and should be used in conjunction with the lists of problems and vulnerabilities in Chapter IV:

1. Teenage mothers, particularly if primiparous and under age 17.
2. Unwed mothers, whether or not they plan to keep the infant.
3. Premature infants, especially those with complications.
4. Infants with congenital abnormalities.
5. Any illness or defect requiring continued hospitalization and extended mother-infant separation.
6. Difficulty with pregnancies, especially involving the loss of an infant; induced abortion (therapeutic or not); habitual abortion; fertility problem or miscarriage, especially if a long wait for a child is involved or the parents believe this is their "last chance;" post partum depression in any pregnancy.
7. Serious problems during pregnancy:
   (a) Medical (toxemia, diabetes, Rh incompatibility, etc.)
   (b) Psychosocial (deaths or losses in family, marital separations, disturbing moves, etc.)
8. Serious marital problems; question about paternity, husband deserted, etc.
9. Poverty, especially if limited prenatal care was involved, as well as particularly intense feelings about discrimination.
10. The parent, especially the mother, losing a parent in early childhood.
11. Psychopathology.

Parent-child relations often are adversely influenced by psychopathology in a parent. One negative outcome of the phasing out of mental hospitals and the maintenance of mental patients in the community has been the fact that many families, through their inability to cope with the mentally ill patient in the home, have seriously endangered the mental health of their children.

Children who were born to mental patients when either the mother or father was initially hospitalized have been studied to see if difficulties have been encountered by the child with a mentally ill parent at home.[3] In one of three of these families with mentally disturbed parents, at least one child has had severe psychological difficulties. Even where treatment was provided to both father and mother, the children were largely ignored. A very early return to the home of heavily tranquilized mothers who are then responsible for the care of their children, usually without additional help, can have deleterious effects upon the children.

While "high-risk" parents can be identified easily through social histories, many of them turn out to be adequate nurturing parents. Somehow they develop the capacity for parenting. They have strengths which the physician should attempt to identify and encourage.

There are other parents who may exhibit no apparent deficits related to the aforementioned clues, but have more than usual difficulty in developing parenting skills. In such cases, the physician should be alert to other risk indicators; e.g., hostility toward a child when a new baby arrives; heightened anxiety over future events, such as the child's adaptability in school; and parental "clinging" to the child.

Below are specific questions that can elicit responses from the parent or parents to help the physician assess parental capabilities at different points in child, parent and family development. The physician can use such questions particularly as a screening instrument to identify additional "high risk" situations. Although they have a somewhat logical sequence, the questions may be asked in any order. Perhaps none of these questions will be relevant to a given situation; however, by asking these or similar questions, the clinician can indicate his interest in the parents as persons and in their specific concerns.

The questions are arranged in pairs, with each set dealing with the parents' attitudes and behavior and also with the child's behavior. Although the questions regarding parents' attitudes are phrased so as to avoid defensive responses, the clinician may feel that with certain anxious or angry parents he should first ask questions regarding the child, and come back later to questions dealing with parental feelings. The clinician also should make an independent judgment in each case as to whether to use the questions in conjunction with, or apart from, the "family inventory" outlined in Chapter I.

1. (a) How does it feel to be the parent of a child at this stage? What is the most frustrating thing about this stage?
   (b) Tell me about your child at this stage.
2. (a) What were your previous experiences with children at this stage?
   (b) How does he compare with the other children?
3. (a) What do you do and how do you cope? How does this seem to work? Have you thought about extra resources (day-care, nursery school, etc.)?
   (b) How does he react to people; show his will; move out; show his interests; express his individuality?
4. (a) Do you think it's easier to bring up a boy or a girl?
   (b) What kind of boy/girl things does he/she do?
5. (a) What do you do together as a family? What about TV?
   (b) How does he fit in the family? Whom is he more like?
6. (a) With whom do you discuss family problems?
   (b) To whom does your child talk when he has a problem?
7. (a) What do you think it's going to be like for you and your children in the future?
   (b) What are your thoughts about how he will be in the next few years?

The clinician can take into account certain check-points (See Table III) when asking such questions to assess parental capacities.

Table III

CHECK-POINTS FOR CLINICAL ASSESSMENT OF PARENTAL CAPACITIES*

Points in Child Development	Parental Capacities to be Assessed
Pregnancy and delivery	Beginning maternal attachment: readiness for parenthood.
Early infancy	Capacity to learn cues, perceive needs and continue attachment and bonding.
Late infancy—Toddler	Capacity to accept growth and development, empathize, perceive child as a separate being; development of capacities to support autonomy, set appropriate limits.
Pre-school level	Capacity to accept separation, support beginning individuation, tolerate dependence and regression; development of family roles and capacities, including mourning for losses.
School-age	Capacity to accept growing independence and attachment to parent of opposite sex, teachers and peer group, give increasing responsibility, perceive and actively support child's need for mastery.
Adolescence	Capacity to support search for identity and greater independence, offer guidance and limits, with participation by adolescent; further developments of family roles and capacities; permit young person to leave family, begin to build for selves new life and roles.

*Based on Prugh's delineation[1]

If, after using the questions outlined in Table III, the physician believes there may be problems in parent-child relations or in parenting techniques, he should share his concern with the parents in a nonjudgmental and nonaccusatory way. If the parents cannot comprehend the problem or they reject the notion that a problem exists, it is usually futile to argue with them.

Rather, the matter should be brought up again at subsequent visits for further discussion. When the parents are ready to accept some help, the physician will need to discuss with them whether he should personally do the counseling or refer them to some other professional (see Chapter VII). For parents who are inexperienced or naive in matters of childrearing and do not show overt emotional disturbances themselves, the physician may wish to suggest parental training.

Centers for Parental Training

Several research-oriented centers have been established in various parts of the country to enhance parental skills. Training sessions for mothers and fathers are incorporated in these programs, as are frequent home visits by social workers.

There is evidence that these centers have had a significant effect.[2] Participating mothers have been found to be more sensitive to their children's social, emotional and intellectual needs; more aware of the causes of child distress, and more skillful in comforting their children and in using appropriate community agencies; and more aware of the range of individual differences among children, placing less value on stereotypic expectations.

Children involved have benefited in intellectual and language development, as well as in social and emotional growth, as compared with other children.

The physician may find such a center to be an important resource for some of the families he sees.

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CHAPTER I

CHILDREN AND FAMILY ASSESSMENT: THE FAMILY INVENTORY

The family inventory is an instrument for identifying developmental problems in the child, while assessing the interplay of their multiple causes. The inventory can prepare the family for taking effective remedial steps. It is almost axiomatic that the child who presents for treatment can never be viewed in isolation -- only in the context of the family of which he is a part.

The use of a family inventory will bring out different problems in different cultural groups. It is often difficult, for example, for white staff members to discern the strengths and healthy coping mechanisms of black children. White society may pressure the black child to act white-like to receive the affirmation of the staff and get care. To the black family, change then implies desertion of the family and denial of race.

The commonly mentioned identity problems of black, Spanish and other cultures living in a white environment are accentuated in a health setting unless the problems are recognized and dealt with. The family inventory will clearly demonstrate some of the attitudinal phenomena seen in certain minorities. These groups may have faith in alternative methods of health care. These beliefs may not only keep the family from entering the medical system and asking for health care, but also interfere with the use of medication, physiotherapy, and other types of standardized medical treatment for children.

The family inventory will also suggest that certain problems are more common in some types of families. We are all aware that poor people have more physical illnesses and that this would appear to be a circular phenomenon. However, the distancing and separation from standard health care that occurs in many non-white or non-middle-class families may lead not only to resentment but to the commonality of depression among these various groups. Immigrants and refugees have considerable depression that stems from being separated from their own ties, as well as from the difficulties of being absorbed into the mainstream culture of their new home. Such difficulties are frequently compounded by resentments the physicians harbor in caring for such persons, as well as by lack of understanding of their specific problems.

The facts needed and the techniques for obtaining data for a psychosocial evaluation of a child and his family are not usually found in standard textbooks on physical diagnosis, nor in courses taught in medical school. It would be well for the physician to ask a few leading questions about psychological stress and the emotional climate of the home in his first contacts with the family. From such an approach he can expect to get clues about causes, and to maintain an "open door" to explore multiple causes, should the need to do so arise later.

If the physician has not set the climate for psychosocial exploration during the initial history and subsequent well-baby visits, he should let the parents know, when a developmental problem becomes apparent, that he would like to explore psychological factors that may be operative. He should ask the parents whether they have considered this possibility themselves, and, if they have, what their ideas are.

From: The Physician and Mental Health of the Child, American Medical Association, 1979.

Frequently, with developmental problems, the presenting complaint is vague and unclear, making it necessary for the physician to urge parents and child to describe as clearly as possible what they see as the primary problem, and, if the problem is chronic, what events or changes in the situation made them decide to come in for help at this particular time.

The physician also will ask about any other possible behavioral and emotional symptoms that the parents may have been aware of but did not volunteer in the initial history. In addition, he needs to know about the child's pre-school and primary school adjustment, scholastic success, and the attitude of both the child and the family toward school. If the child has symptoms related to school problems, the physician should request a report from the school covering the child's academic and social adjustments and giving results of any formal testing. Although this report should be in writing, a telephone call often will provide essential supplementary information.

Questions about the child's relationship with other children, including siblings, are important, as are those pertaining to the child's relationship, both positive and negative, with each parent individually and together.

The inventory also will cover the child's playtime interests and activities, his energy supply, his sleep and eating patterns, his mood and mood changes, his awareness of his own sex, his knowledge of the basic biological facts of life, and any habits or bodily concerns that bother the child or the parents.

The physician should ask for a description of a "typical day." He should seek information on the physical and emotional health of the grandparents, and of other significant adults in the child's life. He should ask directly about possible psychologically stressful events. Finally, he should elicit in a non-judgmental way a narrative description of how the parents discipline the child, how they feel about the child, how they feel about one another, and any concerns they have about disruptions or potential disruptions in the marriage or in the family unit. The physician must be sympathetic toward a family's dilemma if he wishes to elicit full cooperation in diagnosis and treatment. Otherwise, one or more family members may feel blamed or "scapegoated," and become defensive or otherwise uncooperative.

Taking a family inventory cannot be learned entirely from reading. It must be learned in the same manner that history taking and physical diagnosis are learned in medical school; i.e., by watching an experienced practitioner perform the task, followed by practice sessions under his supervision.

OUTLINE FOR FAMILY INVENTORY

Information in each of the following areas is relevant to evaluating problems that may present themselves. Ideally, the physician learns much about the past history and the social adjustment of the family members and the family as a unit during formal and informal contacts with them over a long period of time, starting with the first well-baby visit. If the patient is new, however, or presents an entirely new problem, the physician may find it necessary to obtain the information by direct questioning in one to three specifically designated appointments.

It is impossible for the physician to get an accurate assessment of each family member from the usual second-hand description provided by one member only, typically the mother. While it is desirable that the physician interview both parents, at time interviewing has to be done on the basis of expediency. The single-parent family, of course, is one example. Even in this case, it is still worthwhile to make the effort to interview as many persons as possible, including the parent, the child and siblings, individually or in a vraiety of pairs, as well as others who may be part of an extended family.

The following outline is supplementary to, not in place of, the standard medical history. The first categories deal with the child; succeeding categories move on to interpersonal and family relationships.

I. Presenting symptom(s) (problems).
  A. Describe as succinctly as possible in your own (parents') words.
II. Course of symptoms.
  A. Time of onset, if possible.
  B. Describe symptoms since onset.
  C. What thing(s) made you decide to seek help now?
  D. Any additional symptoms?
III. Past History -- any previous psychological or behavioral problems? Illnesses? Operations? Family's reactions to these events?
IV. Psychological inventory of child.
  A. School adjustment.
    1. As described by child.
    2. As described by each parent.
    3. Teacher's report on academic and social adjustment.
    4. Academic and psychological testing already done by school.
  B. Interpersonal relationships.
    1. With peers.
    2. With siblings.
    3. With mother.
    4. With father.
    5. With significant others.

- C. Activities and interests.
  - 1. Energy level
  - 2. Moods and mood changes.
  - 3. Sleep and eating patterns.
  - 4. Playtime interests and activities.
  - 5. Sex education to date.
  - 6. Habits
  - 7. Bodily concerns.
  - 8. Description of a typical day.

V. Psychological inventory of family.

- A. The parents.
  - 1. Date and reasons for marriage.
  - 2. The development of the relationship.
  - 3. Current feelings about one another.
  - 4. Financial adjustment and employment history.
  - 5. Sexual adjustment.
  - 6. Contraception and family planning.
  - 7. Attitudes about discipline.
  - 8. Feelings toward this child.
  - 9. Feelings toward the siblings.
  - 10. Any separations, actual or contemplated.
  - 11. Religious background.
- B. The Grandparents.
  - 1. Current health and social adjustment.
  - 2. Relations to this child and the family.
- C. The siblings.
  - 1. Names and ages.
  - 2. Current health and social adjustment.
  - 3. Relationship with this child.
- D. Housing.
  - 1. Neighborhood character.
  - 2. Number of moves.
  - 3. Current amount of space in the house.
  - 4. Sleeping arrangements.

The physician may also find certain screening questions helpful to use in conjunction with the family inventory. Samples of such questions are provided in Table I.

At the time of a crisis, a review of family strengths, problems, and the salient features of the family inventory can be therapeutic in and of itself, because many families will quickly develop insight into the psychological nature of the child's symptoms and intuitively know which steps to take to alleviate the situation.

Even if the family inventory does not produce an amelioration of symptoms, it will be useful in providing clues about causation and in the selection of one of the types of therapy to be described subsequently in this monograph. Because all behavioral and most emotional disorders are multi-determined, however, the physician must keep in mind that the inventory may only furnish leads for additional physiologic or psychologic investigation, rather than reveal definitive etiology.

TABLE I

Sample "Screening" Questions for Various Developmental Levels from Pregnancy To 8 Years of Age*

(A) PREGNANCY

Examples of Questions	Illustration of "At Risk" Response
1. How often do you visit with your parents or other family?	1. Rarely
2. Has anything happened either before or during your pregnancy that causes you to worry about the baby?	2. My husband calls his ex-wife all the time. It upsets me terribly. I'm afraid it will hurt the baby.
3. Do you have any condition that you think might be made worse by being pregnant?	3. Yes, I had a kidney infection last year.
4. What was your reaction when you felt life?	4. I don't remember.
5. Is your husband (the father of the child) much help?	5. He's like another child to take care of.
6. How would you compare the way you feel now with the way you normally feel?	6. Everything hurts. Can't get my housework done. Never sleep now.

(B) NEONATAL PERIOD (up to 4 weeks)

Examples of Questions	Illustration of "At Risk" Response
1. Do you think you can tell your baby's cry from others?	1. No. They all sound the same to me.
2. How does the baby compare with what you imagined he/she would be like when you were pregnant?	2. Very different. He's too active. Never gives me any peace. And he doesn't look like either of us. Wonder if it's mine.
3. As far as you know, is everything OK with the baby?	3. The doctor told me he was fine. But my girl friend lost her baby when he was 4 months old. Maybe something will happen.

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4. Are you getting any help with the baby?	4. I'd rather not. I really don't trust anyone else with him.
5. How has your husband (mate) reacted to the baby?	5. I think he's pretty jealous of him.
6. Are you satisfied with your ability to take care of the baby?	6. He's really a mystery to me. I never know what he wants. He keeps me running in circles.

(C) LATER INFANCY (up to 15 or 18 months)

Examples of Questions	Illustration of "At Risk" Response
1. Does the baby seem to know you? How can you tell? (around 4 months)	1. I'm not sure. He smiles at me, but he smiles at everybody the same way.
2. What does the baby seem to be interested in? (around 6 months)	2. He's pretty quiet. He mostly likes to look at the TV.
3. What does he do when a stranger comes into the room? (about 8 months)	3. Anyone can pick him up. He really doesn't seem to favor anybody very much.
4. Does the baby like to explore things? (about 1 year)	4. Yes, but I'm afraid he'll hurt himself. I've got most things put away and I keep him always in the kitchen or his own room.
5. Does the baby try to get your attention by other ways than crying or try to do things with you?	5. No. not really very often.
6. Has he become fairly regular in his habits of eating, sleeping, elimination, etc.?	6. No. Depends entirely on his mood--or maybe mine. I never know what the day will be like.

(D) TODDLERHOOD

Examples of Questions	Illustration of "At Risk" Response
1. What kind of toys does he seem to like to play with?	1. Well, he doesn't really have any of his ow-. He just uses his older brother's who is six.
2. Will he try to ask for things when he wants something?	2. No. He points or cries.

3. What kinds of things can the baby do for himself? For instance, how well can he feed himself?	3. Oh, I don't think kids can be expected to do much at this age. Besides, he makes such a mess, it's simpler for me to do it.
4. Does he seem to say "no" a lot? How do you handle that?	4. I just can't please him. Everything I do is wrong. Maybe he'll go through the rest of his life just rebelling against everything.
5. How does he act if other kids his age are around?	5. He usually ignores them completely.
6. How does he act if you and your husband go out in the evening?	6. He makes a real fuss. The sitter says it takes hours for him to quiet down. I guess I'm thinking about him the whole time we're out.

(E) PRESCHOOL YEARS

Examples of Questions	Illustration of "At Risk" Response
1. What kinds of things do you still have to do for him?	1. He comes to me for almost everything. He still wants me or my husband to go to the bathroom with him.
2. How does he act with kids his own age?	2. He can't share. Always has to be the boss or he won't play.
3. Does he(she) like to imitate father (mother)?	3. No, I can't think of any examples of that.
4. Does he mostly sleep through the night?	4. No. He gets up a lot. He seems to have nightmares. Or he will wet the bed and then want to sleep with us.
5. Is he showing interest in his own body -- and in his parents or siblings?	5. Mostly, he's afraid of getting hurt. If he falls or cuts himself, he cries a lot and asks a lot of questions about whether it will get well again.
6. What is he interested in? Does he ask lots of questions or want stories to be read to him?	6. He still likes to play with his baby toys. He avoids new things or new ideas. He really wants things to stay the same.

(F) 6 TO 8 YEAR PERIOD

Examples of Questions	Illustration of "At Risk" Response
1. How has he taken to the idea of going to school everyday?	1. He complains and fusses a lot. Full of excuses. We have to stay on top of him the whole time.
2. Does he like to play games with other kids?	2. Yes, but they don't last very long. He likes to change the rules if he's losing and they get angry with him.
3. What does he(she) talk about being when he(she) grows up?	3. We never hear him talk about anything like that. I think he has the idea that he's going to stay with us forever.
4. What is he like when he gets sick?	4. You never saw a bigger baby. He acts like a 2 year old.
5. How does he act toward the baby?	5. He's very jealous. We have to watch him to make sure he doesn't hurt the baby.
6. How does he react to doing chores around the house?	6. We've stopped that. You have to nag so much that it's easier for us to do it.

PERCEPTION OF SELF AND OTHER

Complete the chart below, indicating how you see yourself, how your partner sees you, how you see your partner, and how your partner sees him/herself on the factors listed according to the following continuum.

1	2	3	4	5	6	7
Never or Almost Never True	Usually Not True	Sometimes But Infrequently True	Occasionally True	Often True	Usually True	Always or Almost Always True

	I See Me	Other Sees Me	I See Other	Other Sees Self
1. Self-Reliant				
2. Yielding				
3. Helpful				
4. Defends Own Beliefs				
5. Cheerful				
6. Moody				
7. Independent				
8. Shy				
9. Conscientious				
10. Athletic				
11. Affectionate				
12. Theatrical				
13. Assertive				
14. Flatterable				
15. Happy				
16. Strong Personality				
17. Loyal				
18. Unpredictable				

	I See Me	Other Sees Me	I See Other	Other Sees Self
19. Forceful				
20. Feminine				
21. Reliable				
22. Analytical				
23. Sympathetic				
24. Jealous				
25. Supportive				
26. Has Leadership Abilities				
27. Sensitive to Others' Needs				
28. Truthful				
29. Willing to Take Risks				
30. Understanding				
31. Secretive				
32. Makes Decisions Easily				
33. Compassionate				
34. Sincere				
35. Self-Sufficient				
36. Eager to Soothe Hurt Feelings				
37. Conceited				
38. Dominant				
39. Soft-Spoken				
40. Likable				
41. Masculine				
42. Warm				
43. Solemn				
44. Willing to Take a Stand				

	I See Me	Other Sees Me	I See Other	Other Sees Self
45. Tender				
46. Friendly				
47. Aggressive				
48. Gullible				
49. Inefficient				
50. Acts as a Leader				
51. Childlike				
52. Adaptable				
53. Individualistic				
54. Does Not Use Harsh Language				
55. Unsystematic				
56. Competitive				
57. Loves Children				
58. Tactful				
59. Ambitious				
60. Gentle				
61. Conventional				
62. Speaks Freely About His/Her Feelings				
63. Defensive				
64. Accepts Others' Ideas				
65. Responsive to messages				

CASE: ______________________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

CASE STUDY #1

Mary, age eight, is in second grade, lives with her divorced mother. She has controlled seizures and asthma, and misses a great deal of school. Truancy reports continue to be filed by the school system. Protective services has been involved for two years.

Mary's mother resents county interference and feels she is the best judge of whether the child should attend school. Mary's mother has recurring mental health problems which require hospitalization. She says other people are not going to tell her how to raise her child. She has no car and does not live on a bus line. Few friends and family members are available for support. Mother tells different stories to various helpers regarding what is wrong with Mary.

CASE: ______________________________

A. STRENGTHS

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B. ADDITIONAL INFORMATION NEEDED

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C. SERVICE NEEDS

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D. APPROPRIATE PROFESSIONALS
(Circle Allied Health)

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CASE STUDY #2

(Direct letter from a mother)

Our Mark is eleven years old, and has downs syndrome. He is the youngest of seven children and lives at home.

He has not been a hardship except for monetary services. He attends special classes in public school.

When he was born ARC suggested psychologist services ($10.00 per visit - 110 visits = $1,100.00).

Maybe an exercising stimulating the brain at $10.00 per visits - 100 visits = $1,000.00).

Montessori would benefit him also at $10.00 per visit = $360.00. (This was truly the best.)

The Public Schools, heavens a nightmare. He's born an idiot and they make sure and prove it--that is free.

To better his education, pay $160.00 per month x 12 = $1,930.00 per year.

All I want is for him to be trained to read, print, and be accepted socially with well manners.

We applied for SSI and received it only to find out one year later my husband earned $100.00 over the limit. We are still repaying the payments plus schooling, plus all medication. That sure is the pits.

What really can you do to help. We need action to help the family out and to keep the exceptional child home.

CASE: ____________________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
2.	2.
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10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
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CASE STUDY #3

Jane, 21, is moderately retarded, moderately overweight, and lives in a foster home. Her parents have been unable to care for her for the past six years. Jane is graduating in June from the local high school class for the educable mentally retarded. She requires constant supervision and has several behavior problems which her foster home has managed for five years. She is hyperactive, loses her temper easily, requires supervision of all personal self care skills, and occasionally bites people.

Her foster mother is moving and requesting Jane be moved in June to another foster home. County social services have arranged for ARC to be her guardian.

After numerous attempts, social services has been unable to find a foster home within the county or surrounding counties. The state institutions for DD have denied her admission, saying she is not appropriate. There are no openings in local group homes.

CASE: ______________________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
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3.	3.
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5.	5.
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8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
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CASE STUDY #4

John, age seven, lives at home with his parents and two brothers aged 5 and 9.

John attends a local public school and is enrolled in a special class for emotionally disturbed children. He is having numerous problems in school. He frequently leaves the building on his own and throws temper tantrums. A variety of educational specialists and the school psychologist are all involved. The parents and John receive counseling from the Department of Social Services, but are extremely frustrated and ready to "give up on John."

CASE: ____________________

A. STRENGTHS

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B. ADDITIONAL INFORMATION NEEDED

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C. SERVICE NEEDS

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D. APPROPRIATE PROFESSIONALS (Circle Allied Health)

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CASE STUDY #5

Kyle lives at home with his parents who have devoted eight years to his well being.

Kyle has cerebral palsy, microcephaly and mental retardation.

Kyle is an eight year old, non-verbal, non-toilet-trained child who is very personable and outgoing with those he is familiar with.

He attends the local public school special education classes.

Because Kyle has been primarily dealt with on an individual one-to-one basis, he demonstrates frustration when self-directed activity is expected of him. When attention is given another child (i.e., feeding), Kyle will often prompt personal attention (i.e., dropping his spoon as though unable to feed himself).

Kyle has limited attention span. He is not able to imitate sounds other than b, m, and k, or the vowels, after three years of speech therapy.

Due to Kyle's heel cord lengthening, he ambulates with a foot slap. Kyle's feeding skills are limited because of incoordination. Fine motor activities are being worked on at the present time.

Kyle has difficulty sitting at 90 degrees. His physical therapy program consists of stretching exercises three times a week.

CASE: ____________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
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3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
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CASE STUDY #6

Gertrude is 20 years old and is mildly-high moderate retarded. She lives at home with her parents in a rural area, seventy miles from an urban area. She first came to the attention of the county social services agency due to her drinking, promiscuity, and her involvement in a series of thefts. She was in jail until the trial, found guilty, placed on probation and returned to live with her parents.

Gertrude is able to speak, take care of herself, and go into the community with supervision. She loves records and money. She has been sexually active since age 15 with a variety of men. Gertrude's parents are concerned but are conservative and have taken no steps to prevent pregnancy.

Gertrude's parents contacted the local social services department who indicated they had no suggestions to solve these problems. The county social services agency stated they had a waiting list at the guidance clinic for counseling. The clinic is seventy miles away.

CASE: ____________________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
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9.	9.
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CASE STUDY #7

A four year old boy, Li, a Viet Nam refugee, was removed from the home of his sister and brother-in-law because of child abuse. Li speaks very little English. He has been in this country three months. Sponsors were found by a local voluntary agency to act as foster parents. The Court has ordered counseling for the sister and brother-in-law.

The county social services department has the responsibility to arrange for counseling. A worker in the agency has been assigned as counselor. Another worker in the agency was previously involved in finding the foster parent sponsor. Li has recently begun acting up and causing problems since he arrived at the foster home two weeks ago.

CASE: ____________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
2.	2.
3.	3.
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5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
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9.	9.
10.	10.

CASE HISTORY #8

Sally, age two, lives on a farm in rural Wisconsin with her parents. She has Down's Syndrome and has lots of respiratory problems, especially during the winter. When these problems are under control, she's a very pleasant child.

Sally started cutting teeth when she was 13 months old and now has 8 teeth. Her mother has kept her on the bottle supplemented with cereal and fruit.

Sally only started sitting up when she was 20 months old.

Sally's parents' only outside contact is with Sally's widowed grandmother. Grandmother says Sally will always be a baby.

Sally's parents would like to have another child but are not sure if they should. They have not asked the doctor what he thinks because they are afraid he will want to take Sally away from them. The doctor wanted Sally put in an institution at birth. They only see the doctor when necessary for Sally's respiratory problems.

CASE: ______________________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
4.	4.
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CASE HISTORY #9

Stacee, 26 mos. old. Lives with parents and 3½ year old sister in a rural area.

Her sister has been throwing temper tantrums the past 6 months. Stacee has Cerebral Palsy, Spastic Quadriplegia with Athetosis.

Intelligent, non-verbal girl who expresses herself with her eyes, gestures, and a few sounds.

At age 11 months was seen in the Cerebral Palsy Diagnostic and Evaluation Clinic. Members of the evaluation team include neurodevelopmentally trained occupational, physical, and speech therapists, pediatric neurologist, pediatric orthopedic surgeon, opthalmologist, audiometrist, and is headed by a pediatrician who specializes in cerebral palsy. A neurodevelopmentally trained occupational therapist who will provide therapy and support to the family in the home between clinic visits is also present with the family during diagnostic and follow-up visits.

The home therapist visited the family within a week following the initial evaluation to answer questions and establish a schedule to visits.

During the past 15 months, the therapist has shown and assisted the parents with:

-handling and positioning techniques to allow increased movement and improved function.

-feeding skills, techniques to facilitate oral development and oral motor control.

-rolling with rotation skills.

-suggestions for sitting and standing stabilization.

Stacee is rapidly acquiring new skills in the area of communication. Her father has been extremely helpful in adapting and building equipment for Stacee.

CASE: ______________________________

A. STRENGTHS	B. ADDITIONAL INFORMATION NEEDED
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

C. SERVICE NEEDS	D. APPROPRIATE PROFESSIONALS (Circle Allied Health)
1.	1.
2.	2.
3.	3.
4.	4.
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CASE STUDY #10

John is a bright, highly social six-year old whose birth defects have resulted in a severe speech problem which may be affecting his adjustment in school. He has associated visual, hearing and motor problems. The following observations were made by the Multiclinic Treatment Team.

Psychology

John's teacher indicated that in the classroom he evidenced difficulty in attending. He is highly distractable, wanders around the room visiting with friends, and does not work well independently.

John's father stated that there were no psychological problems with John, and that problems his teacher reports are a function of John's age.

Audiology

John has a history of middle ear problems and accompanying hearing loss, beginning approximately at age two or three.

Genetics

John's syndrome can be defined as a median cleft face syndrome which can be seen in the face as hypertelorism, cleft lip, palate and nasal groove defects. This syndrome is usually sporadic but some autosomal dominant, chromosomal abnormality and polygenically inherited (many genes involved) syndromes have similar features.

John's father was interviewed about the family history. Since he was adopted he has no information about his side of the family. No incidence of cleft palate or similar facial abnormalitiies were recorded on the mother's side of the family.

Therefore, John's syndrome is most likey a sporatic incident, with little risk of recurrence in other offspring of these parents.

Occupational Therapy

John was reported by the teacher to "need improvement in skills like handwriting, coloring, cutting, and pasting." Therefore, in occupational therapy he was given several tests to evaluate his fine-motor coordination and other neurological tests relating to fine-motor coordination. Other tests given to John indicated he seems to have problems with motor planning, i.e., knowing where and when to move his limbs, that would contribute to the gross motor problem.

Speech Pathology

John's speech is unintelligible much of the time. Contributing to the unintelligibility is a significant degree of hypernasality and nasal emission (due to escape of air through the nasal passageway) and misarticulations of several phonemes.

UNIT V: REFERRAL

GOALS AND OBJECTIVES

Information Exchange and the Referral Process,
Part II: Networking Strategies

Purpose:

To have participants define the problem for referral and identify the steps to be taken in making an appropriate referral.

Specific Objectives:

Through the case study activity, participants will:

1. Be able to define the problem;
2. Identify appropriate referral services; and
3. Describe referral and follow-up procedures for children and youth with various handicapping conditions.

In addition, at the conclusion of this session, participants should:

1. Be more sensitive to others' perceptions of the Allied Health professional's role in child-find, referral, and advocacy initiatives.
2. Become more willing to cooperate with other health-related services and education professionals in providing health and education-related services for children and youth with handicapping conditions.
3. Be more sensitive to the need to utilize the parents' expertise and to work closely with them in making recommendations for referrals.
4. Be more sensitive to and understand the ethical considerations in the referral process.

REFERRAL PROCESS AND STRATEGIES

I. Referral Resources

  A. Know the referral process in your agency

    1. Who is the referral contact?
    2. How do referrals go out of your agency?
    3. How do referrals come into your agency?
    4. What forms are used for referrals?
    5. How are follow-ups processed?

  B. Make a list of local resources

    1. General/generic resources

      a. day care for working mothers
      b. local physicians, dentists
      c. YMCA, Big Brothers/Sisters
      d. etc., etc.

    2. Specialized resources

      a. special ed. classes
      b. respite care
      c. disability organizations (e.g., Assn for Retarded Citizens)
      d. home trainers
      e. etc., etc.

  C. Develop card file on resources

    1. List organization and contact name
    2. Telephone numbers and hours of service
    3. List services provided
    4. Additional information that would be helpful to parent

- D. Know referral process of resources to be used
  1. Who is the contact person(s)?
  2. What forms/letters do they require?
  3. How responsive is the agency?
  4. What is their follow-along policy?

II. Informal Referral - in this process the information on resources is provided to the parent, but the responsibility is on the parent to make contact and follow through.

- A. Inform parent of generic services available in community, in general terms.
- B. Inform parent of specialized services available in community, in general terms.
- C. Give the parent specific information (i.e., contact name and telephone number) on generic services.
- D. Give the parent specific information (i.e., contact name and telephone number) on specialized services.

III. Formal Referral - in this process the responsibility is both on the parent and you as the referrer.

- A. Offer to contact generic services for the parent (by telephone).
- B. Offer to contact specialized services for the parent (by telephone).
- C. Formal referral - letter or referral form.

IV. Referral Process

- A. Who is going to take the child to the referred agency (you, parent, both)?

B. Release of information

1. Be specific of what information is needed.
2. Don't ask for more than necessary.
3. Remember - parents have feelings, need for privacy, and are proud folks.
4. Confidentiality - please remember to get parent permission to share information about their child.
5. Release Forms - they must be signed and dated.

C. Parent's role in referral process

1. Involve parents all the way.
2. Help parents understand services available and how to obtain them.
3. Listen to parents in understanding needs of child.
4. Remember - Remember
    a. it is not easy for parents to be told they have a child with special problems
    b. parents may refuse a referral for testing, etc., because of previous bad experience
    c. you see the child a short time and parents have the rest of the day

V. Follow up on Referral

A. Parent may call you back

1. To thank you
2. To express negative thoughts
3. To get clarification of information received
4. To get referral to another resource
5. Just to talk

B. Your responsibility
  1. Check with referral agency
    a. see if parent showed up
    b. see if additional information is needed
    c. general reaction to referral
  2. Check with parent
    a. general reaction
    b. questions/concerns
    c. additional assistance needed

IV. Resources - refer to notebook
  A. National organizations/agencies
  B. Regional agencies
  C. Staff organizations/agencies
  D. Local organizations/agencies

UNIT V: REFERRAL

GOALS AND OBJECTIVES

General Session IV: Information Exchange and the Referral Process, Part II: Networking Strategies (continued)

Purpose:

To provide information regarding appropriate strategies for making a referral, including referral sources for children with specific handicapping conditions.

Specific Objectives:

At the conclusion of this session, participants should:

1. Be able to identify referral sources within their particular health facility and community.
2. Understand and be able to implement procedures for making referrals for appropriate educational and health-related services, consistent with their professional role.
3. Be able to identify local, regional, and national resources for services for children and youth with handicapping conditions and their families.
4. Be able to identify their state's special education programs, policies, and procedures for providing services to children and youth with handicapping conditions and their families.
5. Be able to identify and utilize networks of community, parent, and disabled consumer groups to assist and support parents and siblings of handicapped children and youth.
6. Understand and be able to clearly communicate with parents and their handicapped child/youth about state and federal legislation, their rights under the legislation, and available education and health-related services in their community.
7. Understand and be able to facilitate the parents' involvement throughout the referral process.

UNIT V: REFERRAL

RESOURCES

- Chapter on "Referral" from: When You Care for Handicapped Children.
- Listing of National, Regional and State organizations concerned with handicapped citizens.
- State Age Requirements for Educating Handicapped Children & Youth.
- Facts You Should Know about Tax Deductions for your Handicapped Child, by the Parent Information Center.

REFERRAL

From: When You Care for Handicapped Children. Reproduced with permission of Texas Department of Human Resources, Family Self-Support Branch.

REFERRAL IS IMPORTANT

As a child care provider you will probably have occasions to refer parents and their children to other agencies. You may need to refer children for child assessment, health services, therapy services and/or educational testing services.

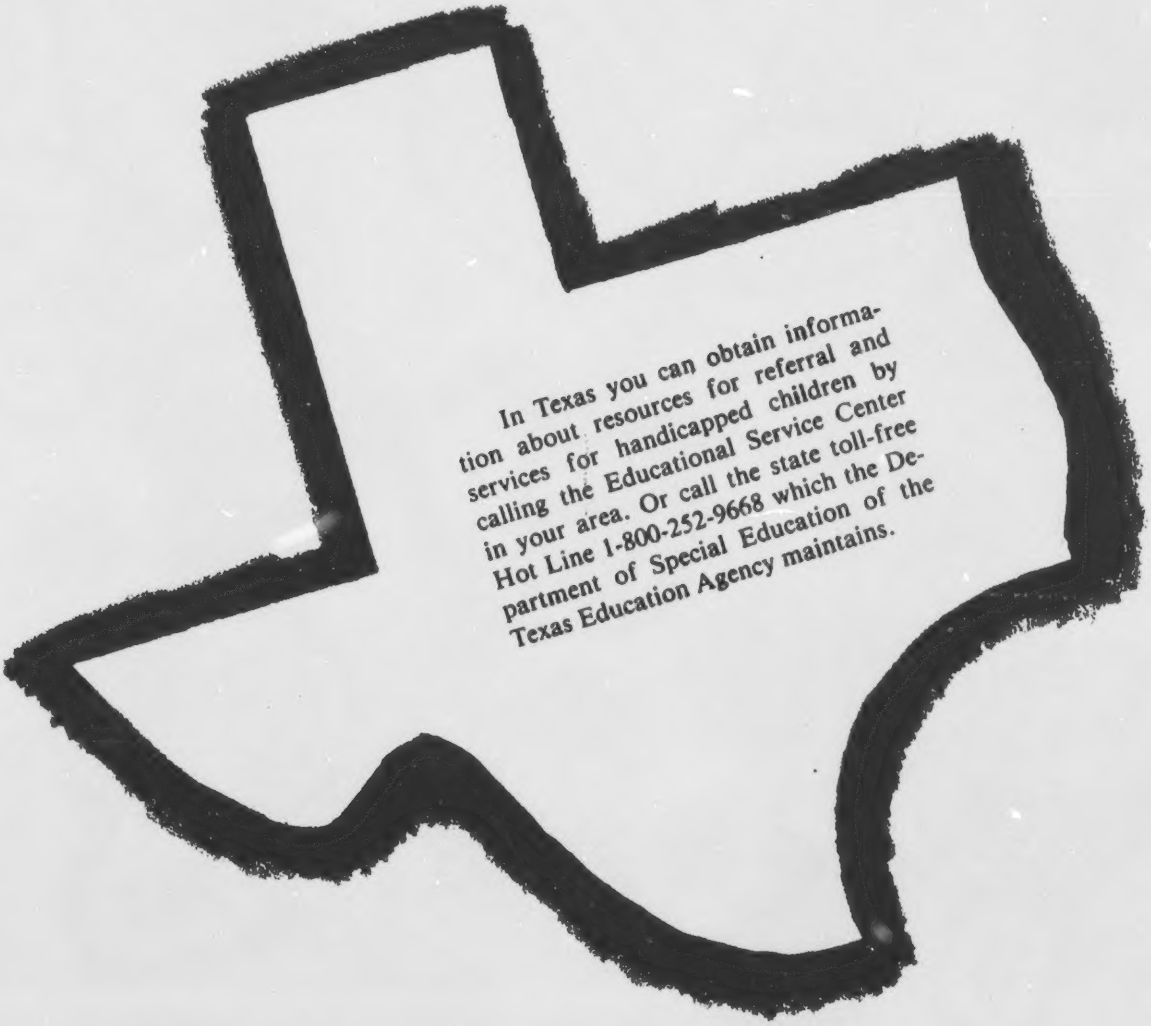
To prepare yourself, you will want to make a referral list, know where to locate agencies for referral and know the procedure to follow when making a referral. Such information will help in obtaining the best services quickly and with the least amount of confusion. When referring children it is also important for you to involve the parents in the referral process.

THE STEPS IN REFERRAL

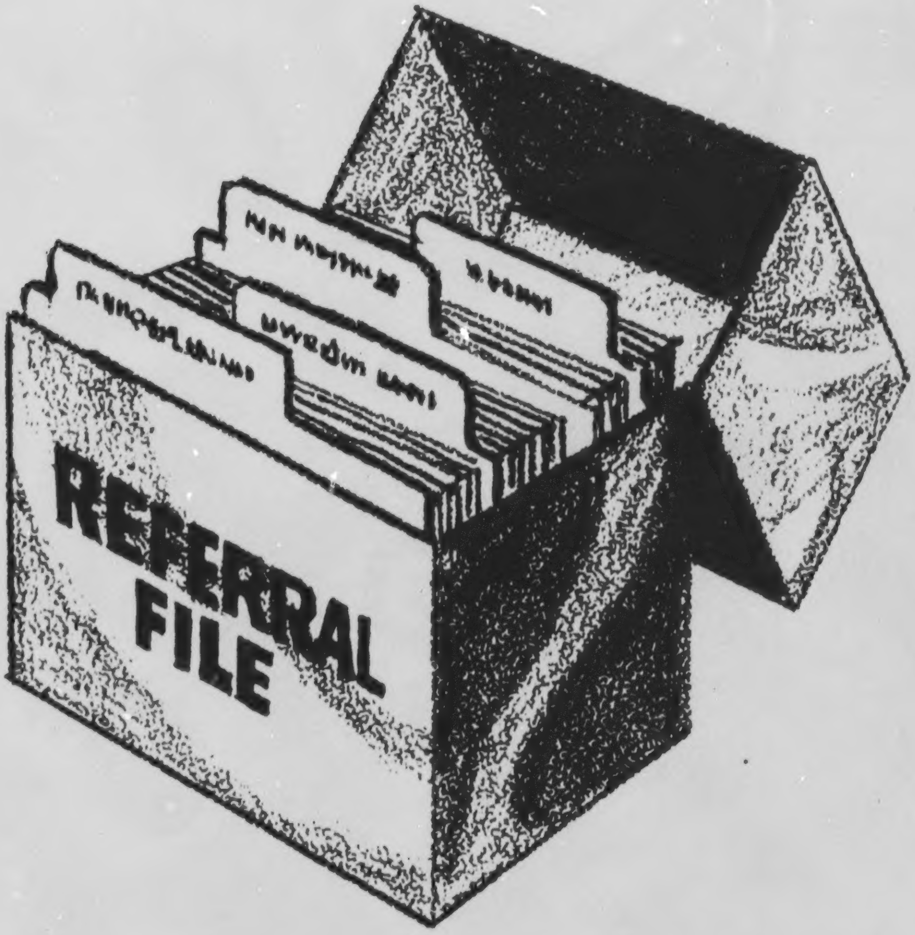
Identifying Local Procedures

Before making a referral, find out if a referral procedure has already been developed for you. Many agencies and programs have a special support staff to identify resources and to assist parents. In some programs the center director or day home supervisor may handle referrals. In still other instances the direct caregiver may be the one who handles the referral process.

If your procedure requires another individual to make the referral or do some preliminary testing you will want to meet with that person to share your concerns and observations about the child, and to talk about the reason for referral. The other person may also ask you to have the parents sign a permission for testing. Because you may be the one the parent knows, you can help by introducing the parent to the support staff.



In Texas you can obtain information about resources for referral and services for handicapped children by calling the Educational Service Center in your area. Or call the state toll-free Hot Line 1-800-252-9668 which the Department of Special Education of the Texas Education Agency maintains.



Setting Up a File of Service Agencies

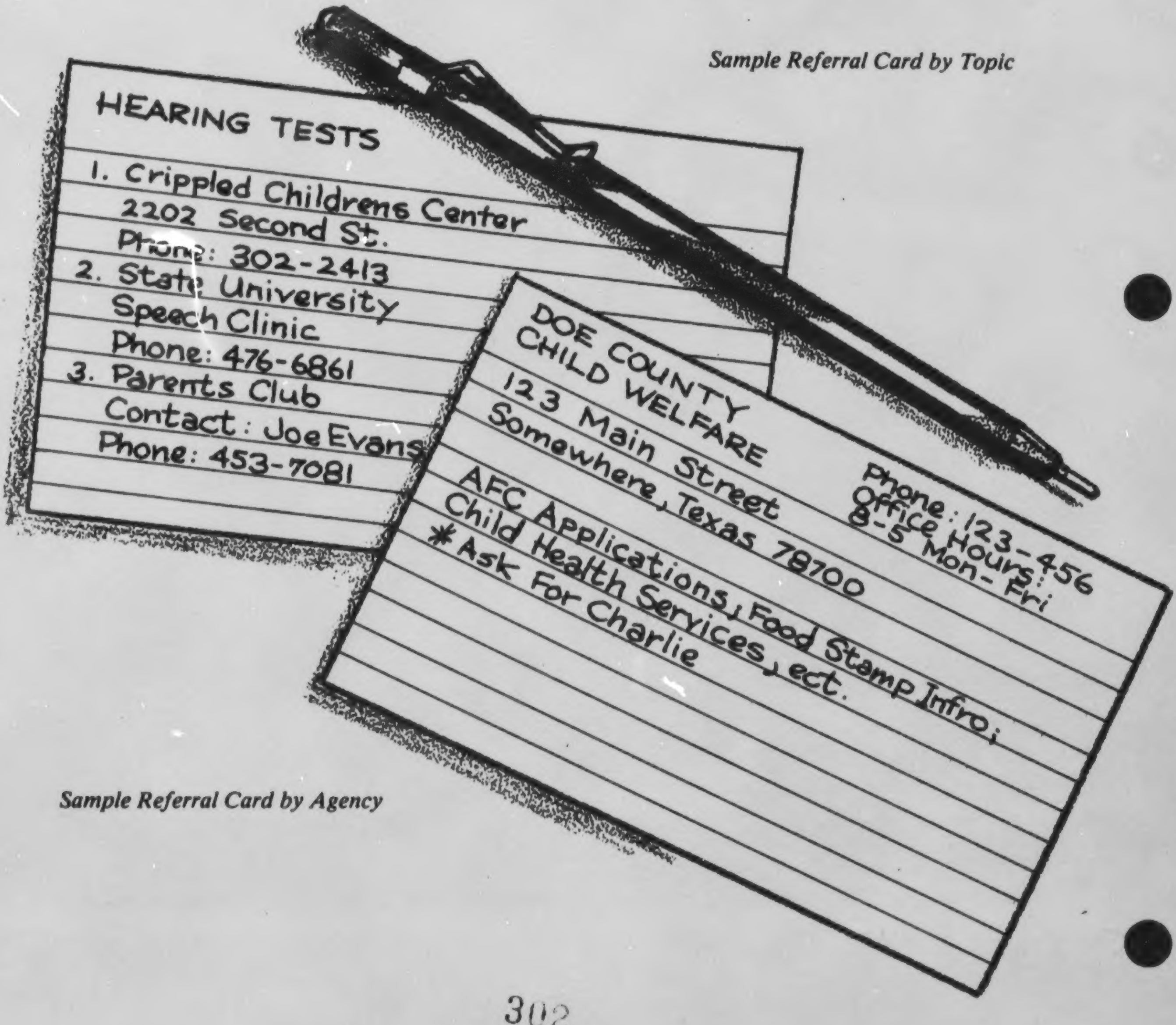
In some cases there may not be an established referral procedure or a support staff. You may be the one to refer the parent for assessment and services. So that both the child and family receive the best help possible, be sure you have information about all the services available to families in your community. There may already be a general source for making a referral list, such as a directory from a local public agency. The center director, your supervisor, program nurse, social worker or other caregivers may know places in your community where children can be referred. For day care staff who are not based in a center, the public health nurses, local doctors and Department of Human Resources staff are valuable sources of referral information.

Because of Law 94-142, the first referral agency you should include on your list is the local public school. Local public schools now provide assessment for potentially handicapped children from age 3 through 21. For deaf, blind, and deaf/blind children these services are provided from birth. If a child is assessed by the public school and found to be handicapped, the school will provide the services that child needs.

In making your own referral list, one convenient method is to write the name and address of each community agency or service group in your area on a 3 × 5 inch card. Arrange the cards in alphabetical order and place them in a box. With this method you will be able to refer quickly to the card when necessary. You can also group cards together by topic. For example, group together the names of agencies that provide counseling or those agencies that can help with medical bills, and so on.

The examples of referral cards show ways to list the information. Check with each agency or group on your referral list **each year** to be sure you have correct information. Remember to put down the address, telephone number, office hours, cost, eligibility criteria (whether parents must be in a certain income bracket to receive services), contact persons, and any special information you may need. The last part of this chapter provides a list of resources for assessment and services at the local, county, state, and national levels.

Sample Referral Card by Topic



HEARING TESTS
1. Crippled Childrens Center
2202 Second St.
Phone: 302-2413
2. State University
Speech Clinic
Phone: 476-6861
3. Parents Club
Contact: Joe Evans
Phone: 453-7081

DOE COUNTY
CHILD WELFARE
123 Main Street
Somewhere, Texas 78700
Phone: 123-456
Office Hours:
8-5 Mon-Fri
AFC Applications; Food Stamp Infro;
Child Health Services, ect.
* Ask For Charlie

Sample Referral Card by Agency

Communicating with the Referral Agency

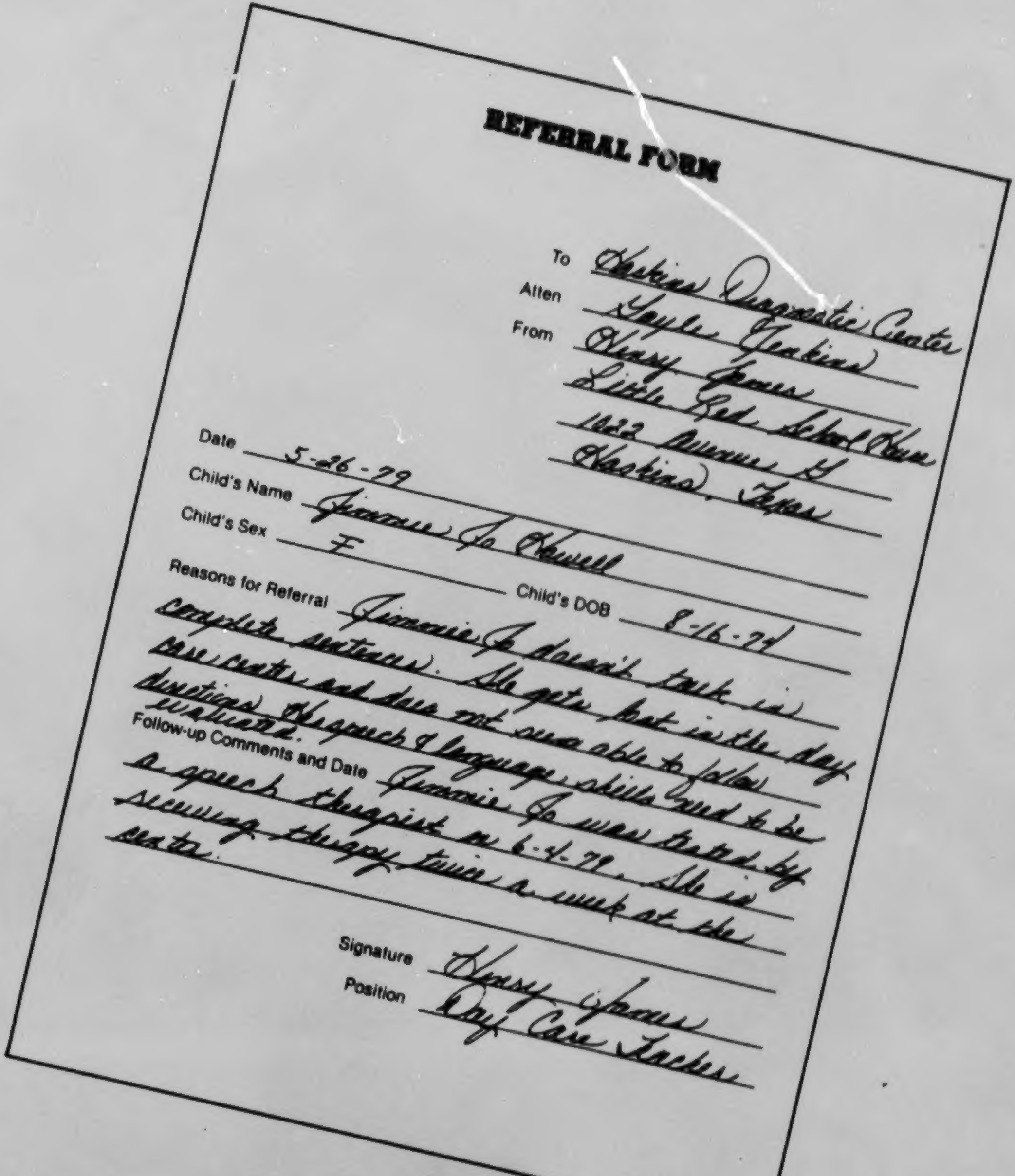
Once you have identified the resources in your community you will need to be able to communicate with these agencies and use them effectively. You will first want to become familiar with each agency's referral procedure. You may then want to develop a referral form that you can send to the agency explaining your reason for referral and telling how to contact you for further information.

Knowing the referral procedure at each agency will save you and the parent much time and frustration. If you know the procedure you will also be better able to prepare for the referral and give parents the support they need. The following is referral information that you will want to obtain and write down on the 3 × 5 card.

1. Contact person in agency.
2. Days and times that referrals or intake applications are taken.
3. Documentation (birth certificates, Medicaid Card) a parent will be required to bring on the first visit.
4. Approximate amount of time referral or first appointment will take.
5. Whether or not a referral form needs to be filled out before the first visit (some agencies want you to call in your referral so that they can send you and/or the parent a referral form or questionnaire to fill out before coming).

If the agency you are referring to has not asked you to complete a referral form, you may want to send them one of your own. A referral form is a means of communication. It is a way of telling the referral agent what you have already observed, what your concerns are and why you have referred the child or family. The most important information to include is a description of the behavior which made you feel the child needed special services. You may have results from a screening instrument or checklist. This information should be written down and shared with the person who will work with the child. Be sure to have signed permission from the parents to share such information, since it is confidential.

You will also want to include your name, address and phone number so the referral agent can contact you if there are additional questions or suggestions. See the Referral Form example for more details.



REFERRAL FORM

To Haskins Diagnostic Center
Atten Gayle Jenkins
From Henry James
Little Red School House
1022 Avenue G
Haskins, Texas

Date 5-26-79
Child's Name Jimmie Jo Howell
Child's Sex F
Child's DOB 8-16-74

Reasons for Referral Jimmie Jo doesn't talk in complete sentences. She gets lost in the day care center and does not seem able to follow directions. Her speech & language skills need to be evaluated.

Follow-up Comments and Date Jimmie Jo was tested by a speech therapist on 6-4-79. She is receiving therapy twice a week at the center.

Signature Henry James
Position Day Care Teacher

REFERRAL FORM

To ______________________

Atten ______________________

From ______________________

____

____

____

Date ______________________

Child's Name ______________________

Child's Sex ______________ Child's DOB ______________

Reasons for Referral ______________________

____

____

____

Follow-up Comments and Date ______________________

____

____

____

Signature ______________________

Position ______________________

Making the Referral

Once you have gathered information about who the referral agencies are, what services they provide and how to refer to them, you are ready to make referrals. The first step in the referral process is conferring with the parents about your intentions. (See the section on Involving Parents which follows.) During this conference you will also want to decide who will have the primary responsibility for taking the child to the other agency for assessment or services. This may occur in the following ways:

- Parent takes child.
- Caregiver takes child.
- Parent and caregiver take child.

After you have decided who will take the child to the agency, you should ask the parents to sign a release form allowing you to share information about their child with the agency. An example of a release form is provided.

Remember, any screening, testing or other educational information you have about a child is **confidential!** The parent must give you written permission to share that information before you talk to the staff at a referral agency. Talking about a child's abilities or progress to persons outside of your program without parent permission is very risky. All information about a child's abilities must remain confidential unless you have parental permission to share it.

CONFIDENTIAL
CONFIDENTIAL

RELEASE FORM

Date ______________________________

TO WHOM IT MAY CONCERN:

This is to authorize ____

to forward all records concerning testing, academic performance, health information and diagnosis, psychological evaluations and other information as listed, __________

____

____

for my child ____.

These records are to be sent to: ______________________________

____

____

____

____

Signature Of Parent Or Guardian

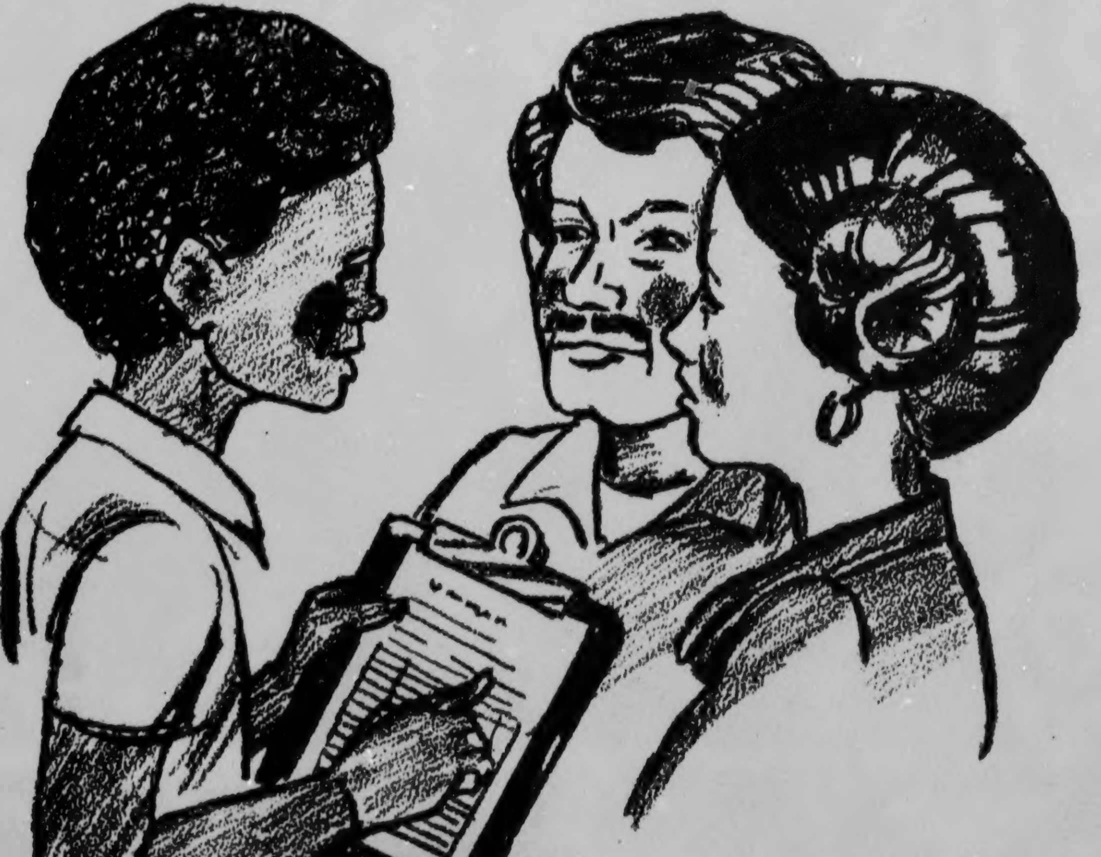
INVOLVING PARENTS

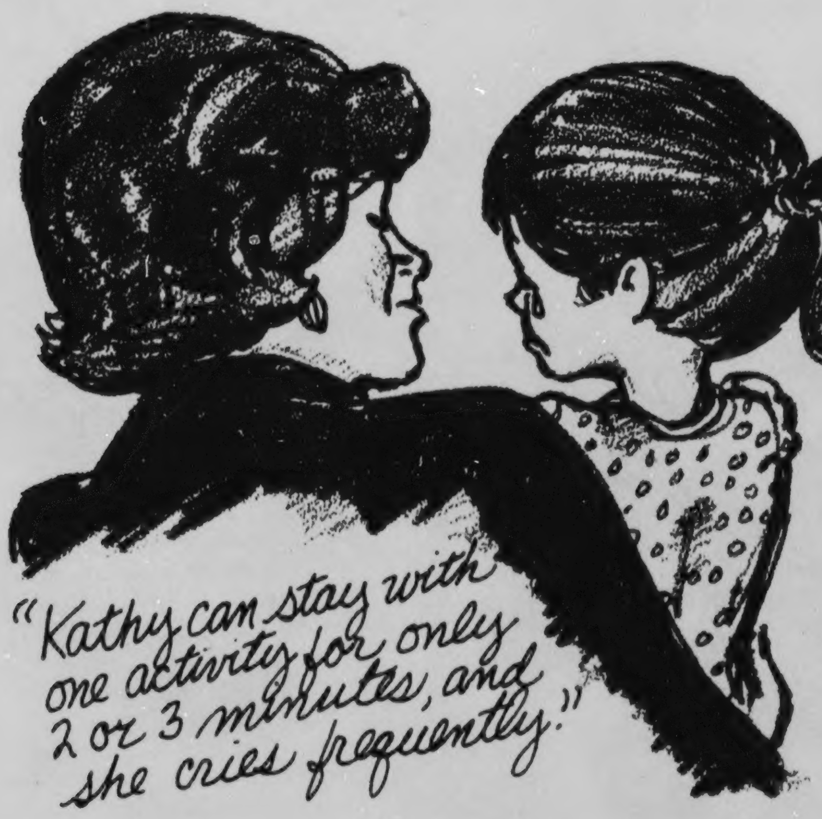
When planning to refer a child it is important to involve parents from the very beginning. Remember that you may only serve a child for a short period of time. If you meet all of the child's needs without involving the parent, you have not taught the parent how to assist the child once the child is out of your care. One of your goals should be to help the parent become confident in asking for services their child needs and become acquainted with procedures for doing so.

Also, remember that parents are your partners in working with children. They are concerned about their child's welfare. Depending on the nature of a referral, parental reactions may vary. In each case you will need to think of the effect of your request on parents. You will want to present your request and information in the most supportive manner to help gain the parents' cooperation.

When you schedule a parent conference, keep in mind that parents, because they love their child and have plans for the future, frequently become upset if someone calls their child "retarded" or "disturbed." A label does not really tell you or the parent anything about how to work with the individual child.

Parents may refuse to have their child tested or referred for special help because of unpleasant experiences they may have had in the past. They may have another child who was tested and treated unfairly in the past. It is only natural for parents to object to letting this happen again. Sometimes parents had their child tested and then were not told the results of the test. You must remember that having a child tested or being told there is a need for special help is not easy for parents. They will be concerned about how the child does on the test.




"Kathy can stay with one activity for only 2 or 3 minutes, and she cries frequently."

They want to know what others think about their child and about their child's future.

When you wish to make a referral or ask permission for testing, the parents will want to know why. Be prepared to explain with examples of the child's behavior and progress at the center or day home. This will help the parents understand the need for special services or testing. When you describe the child's actions remember that it does not help you, the parents, or the child to say things like, "I just can't handle Suzie anymore." This may be true, but it is more helpful to give specific examples of the kind of problems the child has.

For example, you may tell the parents, "Every time we start a new activity, Suzie becomes upset." Or you can say, "Bobby has trouble learning color names, counting to five, and telling a square from a circle."

The most important thing to remember when you talk to parents about their child is to talk about what he or she can and cannot do, never about what you think might be wrong.

For example, rather than telling parents their child is hyperactive or immature, you might say, "Kathy can stay with one activity for only two or three minutes, and she cries frequently."

Keep the parents informed!

Explain to the parents that your goal in referring the child is to discover the specific areas in which the child has trouble and the areas in which the child can succeed. Then you will be able to teach in a way which will help the child learn. Explain how the results of testing will be used. Assure the parents that you will try to answer any questions they may have.

If support staff is not available through your program, contact the local school district, university or one of the associations for the handicapped to see if someone is available to consult with you and the parents about special services and testing. If you are part of a day care program, you may be able to request staff training in this area.

When parents give their permission for testing or special help, be sure to keep them informed about what is being done. After the child has been tested, arrange a meeting between the parents and the person who did the testing or someone who can explain the test results. Or, if the child receives services such as speech therapy, let the parents know you have talked to the therapist, who has suggested ways for you to help the child. Remember that the parents are concerned about their child and have a right to know the results of testing, any special instruction or therapy planned, and how the child progresses.

Sometimes, however, you will meet parents who will not give permission for testing or special help, no matter how hard you try. You must remember that parents have the right to decide what is best for their child. Besides, testing is only one method of finding out how a child learns. If testing is not possible, careful observation of the way a child responds to different tasks at the center or day home may give a caregiver as much information about how a child learns as can be obtained from informal tests.

National Organizations Concerned with Handicapped Citizens

This list of national organizations is not meant to be comprehensive, but rather includes some of the prominent organizations whose efforts focus on improving the quality of life for disabled people.

Voluntary

American Association of Mental Deficiency
5101 Wisconsin Ave., NW, Suite 405
Washington, DC 20016
(202) 686-5400

American Association of University Affiliated Programs (AAUAP)
2033 M St., NW, Suite 406
Washington, DC 20036
(202) 333-7880

American Coalition of Citizens with Disabilities (ACCD)
1200 15th St., NW, Suite 201
Washington, DC 20005
(202) 785-4265

American Occupational Therapy Association
6000 Executive Blvd., Suite 200
Rockville, MD 20852
(301) 770-2200

Closer Look
Box 1492
Washington, DC 20013
(202) 833-4163

Council for Exceptional Children
1920 Association Dr.
Reston, VA 22091
(703) 620-3660

Joseph P. Kennedy, Jr. Foundation
1701 K St., NW, Suite 205
Washington, DC 20006
(202) 331-1731

Mental Health Association
10609 Glenwild Rd.
Rockville, MD 20852
(301) 593-1458

National Association of Private Residential Facilities for the Mentally Retarded
6269 Leesburg Pike, Suite B-5
Falls Church, VA 22044
(703) 536-3311

National Center for a Barrier Free Environment
Information Clearinghouse
11811 Riders La.
Reston, VA 22091
(703) 620-2731

National Easter Seal Society
1435 G St., NW, Suite 1032
Washington, DC 20005
(202) 347-3066

Governmental

Architectural and Transportation Barriers Compliance Board (ATBCB)
Office of Public Information
Washington, DC 20201
(202) 245-1591

Council for State Administrators of Vocational Rehabilitation
1522 K St., NW, Suite 610
Washington, DC 20005
(202) 638-4634

National Association of Coordinators of State Programs for the Mentally Retarded
2001 Jefferson Davis Hwy., Suite 806
Arlington, VA 22202
(703) 920-0700

National Association of State Mental Health Program Directors
1001 3rd St., SW
Room 113
Washington, DC 20024
(202) 554-7807

President's Committee on Employment of the Handicapped
1111 20th St., NW
Washington, DC 20036
(202) 653-5044

President's Committee on Mental Retardation
Regional Office Building
7th and D St., SW
Washington, DC 20201
(202) 245-7596

West Virginia

Mountain State Epilepsy League
1319 Sixth Ave.
Huntington, WV ZIP??

West Virginia ARC
Union Trust Building, Room 400
Parkersburg, WV 26101

UCP of West Virginia, Inc.
P.O. Box 1561
Charleston, WV 25326

NSAC Contact:
Quintin Decker, President
P.O. Box 8152
South Charleston, WV 25303

West Virginia Advocates for the Developmentally Disabled, Inc.
1021 Quarrier St., Suite 411
Charleston, WV 25301

Wisconsin

Wisconsin Epilepsy Association
1245 East Washington Ave.
Madison, WI 53703

Wisconsin ARC
2700 Laura La.
Middleton, WI 53562

UCP of Wisconsin
315 West Gorham
Madison, WI 53703

NSAC Contact:
Ms. Renee Ramsdell, President
4333 Lilac La.
Madison, WI 53711

Wisconsin Coalition for Advocacy, Inc.
2 West Mifflin, Suite 200
Madison, WI 53703

Wyoming

Wyoming Chapter, EFA
P.O. Box 1187
Lander, WY 82520

Wyoming ARC
P.O. Box 1205
Cheyenne, WY 82001

UCP Contact:
Ms. Pat Geesey
1130 Third West
Kemmer, WY 83101

Developmental Disabilities Protection and Advocacy System (DD/PAS), Inc.
508 Hynds Building
Cheyenne, WY 82001

Guam

Marianas ARC
P.O. Box 7358
Tamuning, GU 96911

Advocacy and Protective Services for the Developmentally Disabled
Marianas Association for Retarded Citizens
P.O. Box 7358
Tamuning, GU 96911

Puerto Rico

Epilepsy Society of Puerto Rico
Ruiz Soler
Calle Marginal-Final
Bayamon, PR 00619

Puerto Rico ARC
GPO Box 1904
San Juan, PR 00936

NSAC Contact:
Elba Stephens, President
Pedro A. Bigay 313-D
Urb. Baldrich
Hato Rey, PR 00918

Protection and Advocacy
Puerto Rico Department of Consumer Affairs
Minillas Governmental Center, North Building
P.O. Box 41059
Santurce, PR 00908

Virgin Islands

Virgin Islands DD Council
MCH, CC, & DD Services
Estate SLOB
Christiansted
St. Croix, VI 00820

Committee on Advocacy for the Developmentally Disabled, Inc.
P.O. Box 734
Fredericksted, St. Croix
U.S.A. VI 00840

INFORMATION FROM . . . .

CLOSER LOOK

A Project of the Parents' Campaign for Handicapped Children and Youth

Box 1492
Washington, D.C. 20013

THESE ORGANIZATIONS CAN HELP YOU

In recent years, groups organized by parents of handicapped children and by disabled adults have been trailblazers in the movement to win full acceptance of people with handicaps as members of the human family. These organizations have grown strong through the determination of their members. Parents have helped other parents, adults with disabilities have joined together in advocacy, and all have worked to overcome obstacles of indifference and ignorance. By beaming the public spotlight on severe problems, working for reform and demanding that society respond, they have created a force that has scored remarkable victories — in legislation, in better services, in a more open and aware society.

This list of major national organizations is a source of information and advocacy for handicapped individuals. We urge you to get in touch with the groups that can be most helpful to you — whether you are a parent, a disabled person, a professional, or simply a person who can volunteer time and energy. New groups are coming to our attention all the time; if you cannot find what you need on this list, please contact us and we will try to refer you to an appropriate group.

Ask about chapters near your home. Write for their newsletters and other informative literature. Find out about their wide-ranging national, state and local activities. Whatever your needs — whether services, reports on new research, resources to help a disabled person, information about vocational training, or the encouragement of others who have been through similar situations — see what these groups can tell you. With them, you can help raise awareness of the needs and potential of handicapped children and adults and work for a more responsive and open society.

AUTISM

National Society for
Autistic Children
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, D.C. 20005

CEREBRAL PALSY

United Cerebral Palsy Association
66 East 34th Street, 3rd Floor
New York, New York 10016

DEAF-BLIND

National Association of the Deaf-Blind
2703 Forest Oak Circle
Norman, Oklahoma 73071

National Deaf-Blind Program
Bureau of Education for the Handicapped
Room 4046, Donohoe Building
400 6th Street, S.W.
Washington, D.C. 20202

EMOTIONALLY DISTURBED

Mental Health Association, National
Headquarters
1800 North Kent Street
Arlington, Virginia 22209

The National Alliance for the
Mentally Ill
P.O. Box 1016
Evanston, Illinois 60204

EPILEPSY

Epilepsy Foundation of America
1828 L Street, N.W., Suite 406
Washington, D.C. 20036

HEALTH IMPAIRMENTS

American Cancer Society
777 Third Avenue
New York, New York 10017

American Diabetes Association
600 Fifth Avenue
New York, New York 10020

American Heart Association
7320 Greenville Avenue
Dallas, Texas 75231

American Lung Association
1740 Broadway
New York, New York 10019

Asthma and Allergy Foundation
of America
19 West 44th Street, Suite 702
New York, New York 10036

The Candlelighters Foundation
123 C Street, S.E.
Washington, D.C. 20003

Cystic Fibrosis Foundation
3384 Peachtree Road, N.E
Suite 875
Atlanta, Georgia 30326

Juvenile Diabetes Foundation
23 East 26th Street, 4th Floor
New York, New York 10010

Leukemia Society of America
800 Second Avenue
New York, New York 10017

National Association for Sickle
Cell Disease, Inc.
3460 Wilshire, Suite 1012
Los Angeles, California 90010

National Hemophilia Foundation
19 West 34th Street
Room 1204
New York, New York 10001

National Kidney Foundation
Two Park Avenue
New York, New York 10016

National Neurofibromatosis Foundation
340 East 80th Street, #21-H
New York, New York 10021

National Tay-Sachs Foundation and
Allied Diseases Association
122 East 42nd Street
New York, New York 10017

National Tuberous Sclerosis
Association, Inc.
P.O. Box 159
Laguna Beach, California 92652

United Ostomy Association
2001 W. Beverly Boulevard
Los Angeles, California 90057

HEARING IMPAIRED

Alexander Graham Bell Association
for the Deaf
3417 Volta Place, N.W.
Washington, D.C. 20007

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

LEARNING DISABILITIES

Association for Children and Adults
with Learning Disabilities
4156 Library Road
Pittsburgh, Pennsylvania 15234

The Orton Society, Inc.
8415 Bellona Lane
Suite 115
Towson, Maryland 21204

National Network of Learning
Disabled Adults
P.O. Box 3130
Richardson, Texas 75080

MENTAL RETARDATION

Association for Retarded Citizens
2709 Avenue E. East
P.O. Box 6109
Arlington, Texas 76011

Down's Syndrome Congress
1640 W. Roosevelt Road
Room 156E
Chicago, Illinois 60608

PHYSICALLY HANDICAPPED

American Brittle Bone Society
Cherry Hill Plaza Suite LL-3
1415 East Marlton Pike
Cherry Hill, New Jersey 08034

Arthritis Foundation
3400 Peachtree Road, N.E.
Suite 1106
Atlanta, Georgia 30326

Human Growth Foundation
4930 West 77th Street
Minneapolis, Minnesota 55435

Little People of America
P.O. Box 126
Owatonna, Minnesota 55060

Muscular Dystrophy Association, Inc.
810 Seventh Avenue
New York, New York 10019

National Amputation Foundation
12-45 150th Street
Whitestone, New York, 11357

The National Association of the
Physically Handicapped, Inc.
76 Elm Street
London, Ohio 43140

National Multiple Sclerosis
Society
205 East 42nd Street
New York, New York 10017

National Spinal Cord Injury
Foundation
369 Elliot Street
Newton Upper Falls, Massachusetts 02164

Osteogenesis Imperfecta
Foundation
632 Center Street
Van Wert, Ohio 45891

Spina Bifida Association
of America
343 South Dearborn Street
Room 319
Chicago, Illinois 60604

Tourette Syndrome Association
40-08 Corporal Kennedy Street
Bayside, New York 11361

SPEECH IMPAIRMENTS

American Speech – Language –
Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852

VISUAL IMPAIRMENTS

American Council of the Blind
1211 Connecticut Avenue, N.W.
Suite 506
Washington, D.C. 20036

American Council of the Blind Parents
Rt. A Box 78
Franklin, Louisiana 70538

American Foundation for the
Blind
15 West 16th Street
New York, New York 10011

International Institute for
Visually Impaired 0-7, Inc.
1975 Rutgers Circle
East Lansing, Michigan 48823

National Association for Parents of
Visually Impaired
2011 Hardy Circle
Austin, Texas 78757

National Association for
Visually Handicapped
305 East 24th Street
New York, New York 10010

National Federation of the
Blind
1800 Johnson Street
Baltimore, Maryland 21230

ALL DISABILITIES

American Coalition for Citizens
with Disabilities
1200 15th Street, N.W. Suite 201
Washington, D.C. 20005

The Association for the Severely
Handicapped
1600 West Armory Way
Garden View Suite
Seattle, Washington 98119

March of Dimes Birth Defect
Foundation
1275 Mamaroneck Avenue
White Plains, New York 10605

National Easter Seal Society
for Crippled Children and Adults
2023 W. Ogden Avenue
Chicago, Illinois 60612

People First International, Inc.
P.O. Box 12642
Salem, OR 97309
(503) 378-5143

Cystic Fibrosis Foundation (CFF)
6000 Executive Boulevard, Suite 307
Rockville, MD 20852

Office for Civil Rights

Department of Education
Office for Civil Rights
Switzer Building
Room 5430, 300 C Street, N.W.
Washington, DC 20201
(202) 245-8835

The Office for Civil Rights is the federal agency responsible for enforcing P.L. 94-142. Complaints should be filed with Office for Civil Rights if there are systematic violations of the law in the state or school district that affect a number of children.

Direction Service Centers

Department of Education
Office of Special Education & Rehabilitation Services
330 C Street, SW
Switzer Building, Room 3006
Washington, DC 20201
(202) 472-4650

The Direction Service Project is a computer-assisted information system designed to provide information consultation to parents and teachers of handicapped children (ages 0-21). A listing of all the Direction Service Centers is provided in the section that follows.

Head Start

National Office
Head Start
Administration for Children, Youth,
and Families/Head Start
Office of Human Development Services
P.O. Box 1182
Washington, DC 20013
(202) 755-7790

Indian and Migrant Program Division

Head Start Bureau, ACYF
Department of Health and Human Services
Room 2014 Donohoe Building
P.O. Box 1182
Washington, DC 20013
(202) 755-7715
(Indian and Migrant Programs)

The purpose of Head Start is to provide comprehensive services to low-income and handicapped preschool children. This program awards grants to provide services to preschool children and their families in the following areas: health, education, nutrition, social, and other services as required. A major emphasis is to involve parents to the degree that overall gains in the above mentioned areas are maintained. Parents or others who wish to locate Head Start Projects in their area should contact their neighborhood elementary school, or Direction Service Center. A list of currently funded Head Start programs may also be obtained by contacting the Administration for Children, Youth and Families (listed by Region in following section).

REGION I

States served: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont.

Office for Civil Rights

Department of Education
Office for Civil Rights
140 Federal Street, 14th Floor
Boston, MA 02110
(617) 223-4248

Direction Services

Boston Direction Service
Federation for Children with Special Needs
120 Boylston Street, Suite 338
Boston, MA 02116
(617) 482-2947 or 2915

Head Start

Administration for Children, Youth and Families
Department of Human Health Services
Federal Building, Room 2000
Government Center
Boston, MA 02203
(617) 233-6450

REGION II

States served: New York, New Jersey, Puerto Rico, Virgin Islands

Office for Civil Rights

Department of Education
Office of Civil Rights
Federal Building
26 Federal Plaza, Room 3908
New York, NY 10007
(212) 264-5180

Direction Services

CUNY Direction Service
City University of New York
144 W. 125th Street
New York City, NY 10027
(212) 860-6166

Community Service Society Direction Service
150 W. 105th Street
New York, NY 10025
(212) 666-1300

Syracuse University Direction Service
Center on Human Policy
216 Ostrom Avenue
Syracuse, NY 13210
(315) 423-3851

Head Start

Administration for Children, Youth and Families
Department of Human Health Services
Federal Building, Room 3900
26 Federal Plaza
New York, NY 10007
(212) 264-2974

REGION III

States served: Delaware, Washington, DC, Maryland, Pennsylvania, Virginia, West Virginia

Office for Civil Rights

Department of Education
Office for Civil Rights
P.O. Box 13716
Philadelphia, PA 19101
(215) 596-6787

Direction Services

Delaware Direction Service
Delaware Department of Public Instruction
Townsend Building, Room 143
Box 1402
Dover, DE 19901
(302) 578-5664

Pennsylvania Direction Service
Pennsylvania State Department of Education
236 Union Deposit Mall
Harrisburg, PA 17111
(717) 783-3238

Head Start

Administration for Children, Youth and Families
Department of Human Health Services
3535 Market Street, P.O. Box 13716
Philadelphia, PA 19101
(215) 596-6763

REGION IV

States served: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee

Office for Civil Rights

Department of Education
Office for Civil Rights
101 Marietta Street
Atlanta, GA 30323
(404) 221-2954

Direction Services

Southeast Direction Service
Auburn University at Montgomery
Montgomery, AL 36117
(205) 279-9110, ext: 258

SITES:

Tri-County Direction Service
1940-A Mulberry Street
Montgomery, AL 36106
(205) 263-9700

Tri-Cities Direction Service
P.O. Box 1386
Decatur, AL 35602
(205) 353-2754

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
50 7th Street, NE, Room 358
Peachtree - Seventh Building
Atlanta, GA 30323
(404) 881-3936

REGION V

States served: Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin

Office for Civil Rights

Department of Education
Office for Civil Rights
300 South Wacker Drive
8th Floor
Chicago, IL 60606
(312) 353-2520

Direction Services

High/Scope Educational Research Foundation
600 North River Street
Ypsilanti, MI 48197
(313) 483-1210

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
15th Floor
300 South Wacker Drive
Chicago, IL 60606
(312) 353-1781

REGION VI

States served: Arkansas, Louisiana, New Mexico, Oklahoma, Texas

Office for Civil Rights

Department of Education
Office for Civil Rights
1200 Main Tower Building
19th Floor
Dallas, TX 75202
(214) 767-3951

Direction Services

Austin Direction Service
Texas Education Agency
1028 E. 12th Street
Austin, TX 78701
(512) 474-6836

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
1200 Main Tower Building, 20th Floor
Dallas, TX 75202
(214) 749-2492

REGION VII

States served: Iowa, Kansas, Missouri, Nebraska

Office for Civil Rights

Department of Education
Office for Civil Rights
12 Grand Building
1150 Grand Avenue - 7th Floor
Kansas City, MO 64106
(816) 374-2223

Direction Services

Midwest Direction Service
Midwest Regional Resource Center
Drake University
1332 26th Street
Des Moines, IA 50311
(515) 271-3936

SITES:

Jackson County Direction Service Ctr.
Mercantile Bank Building
3640 Noland Road
Independence, MI 64055
(816) 833-4415

Black Hills Direction Service Center
2040 W. Main, #110
Rapid City, SD 55701
(605) 341-3944

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
3rd Floor Federal Building
601 E. 12th Street
Kansas City, MO 64106
(816) 374-5401

REGION VIII

States served: Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming

Office for Civil Rights

Department of Education
Office for Civil Rights
Federal Building
1961 Stout Street
Room 11085
Denver, CO 80294
(303) 837-5695

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
Room 7417, 1961 Stout Street
Denver, CO 80202
(303) 837-3106

REGION IX

States served: Arizona, California, Hawaii, Nevada, Pacific Trust Territories

Office for Civil Rights

Department of Education
Office for Civil Rights
1275 Market Street - 14th Floor
San Francisco, CA 94103
(415) 556-8586

Direction Services

Los Angeles Direction Service
University of Southern California
600 South Commonwealth Ave., Suite 1304
Los Angeles, CA 90005
(213) 645-9044

San Mateo County Direction Service
Del Green Associates, Inc.
118 Chess Drive, Suite 200
Foster City, CA 94404
(415) 952-7878

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
Room 143 Federal Building
50 United Nations Plaza
San Francisco, CA 94102
(415) 556-6153

REGION X

States served: Alaska, Idaho, Oregon, Washington

Office for Civil Rights

Department of Education
Office for Civil Rights
1321 Second Avenue
M/S 723
Seattle, WA 98101
(206) 442-2990

Direction Services

Northwest Coordination Office for Direction Service
University of Oregon
1590 Willamette Street
Eugene, OR 97401
(503) 686-5641

SITES:

Educational Service District #12
Vancouver Direction Service
1313 NE 134th St.
Vancouver, WA 98665
(206) 574-2371

Portland Public Schools
King Neighborhood Facility
4815 NE 7th
Portland, OR
(503) 288-5167

Northwest Coordination Office for Direction Service
Lane County Direction Service
1736½ Moss Street
Eugene, OR
(503) 686-3598

Head Start

Administration for Children, Youth and Families
Department of Health and Human Services
Arcada Plaza Building
1321 2nd Avenue
Seattle, WA 98101
(206) 442-0838

The section that follows gives a partial state listing of agencies and organizations that provide services to handicapped children and youth. Agencies are listed according to whether they provide information and referral services, are a state, consumer or advocacy agency, or are a parent-support group. Many agencies provide several of these services; for example, the Association for Retarded Citizens is listed as a consumer agency, but it also provides information, referral and advocacy services.

Some of the agencies' functions will be well known, others less so. Therefore, provided below are the purposes of some of those less well known.

(1) The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program

The EPSDT program is a federally sponsored Medicaid program administered by each State, in which Medicaid eligible families may voluntarily participate. In some States, the health department manages the program, in some States the welfare department manages it, and in a few States, a special commission is responsible for the program. The program is intended to provide a comprehensive range of health care services to children of Medicaid eligible families.

(2) Client Assistance Projects (CAP)

The purpose of these projects funded by the federal vocational rehabilitation office is to act as an ombudsman for rehab clients or applicants for services who have been denied rehabilitation services, or are experiencing difficulties with the rehabilitation process.

(3) Protection and Advocacy (P&A) agencies for the Developmentally Disabled

The structure of the P&A agencies varies from state to state, but the majority are private, non-profit and provide a full range of advocacy services, including legal advocacy services. The P&A agencies are an important component to the effort to guarantee and safeguard the rights of persons with handicapping conditions.

STATE AGE REQUIREMENTS FOR EDUCATING HANDICAPPED CHILDREN AND YOUTH.

STATE	AGES	EXCEPTIONS/CLARIFICATIONS*
Alabama	6 to 21	Permissive services for deaf and blind from 3 to 21. Education for 12 consecutive years starting at age 6. If school district offers Kindergarten, then services required at 5.
Alaska	3 through 19	- - - - -
Arizona	Between 6 and 21	If Kindergarten is maintained, then 5. 3-5 permissive.
Arkansas	6 through 21	If Kindergarten program, then 5-21.
California	4 years/9 months through 18	3 to 4.9 intensive services; 19 through 21 if not graduated or completed course of study. 0-3 permissive under Master Plan.
Colorado	Between 5 and 21	Or until graduation; 3-5 permissive.
Connecticut	4 to 18	May serve only until graduation. Hearing impaired beginning at age 3. Starting 9/80 serve until age 21 unless child graduates.
Delaware	Between 4 and 21	Allows services 0 to 21 for deaf/blind and hearing impaired.
District of Columbia	Between 3 and 18; 3-21 by fall 1979	- - - - -
Florida	5 through 17	Beginning at Kindergarten and for 13 consecutive years. Permitted with State funds from age 3.
Georgia	5 through 18	0 through 4 and 19 through 21, permissive.
Hawaii	6 to 20	3 to 5 permissive.
Idaho	5 through 18	5 through 21 by 9/1/80; 0 through 4 at local discretion.
Illinois	3 through 18	3 through 21; 9/1/80
Indiana	6 to 18	- - - - -
Iowa	Birth through 20	- - - - -
Kansas	5 to 21	Through school year during which reach 21 or until completed an appropriate curriculum, whichever occurs first. 0-5 permissive

STATE	AGES	EXCEPTIONS/CLARIFICATIONS*
Kentucky	5 through 17	Permitted to 21
Louisiana	3 through 21	- - - - -
Maine	5 to 20	- - - - -
Maryland	3 to 21	Birth to 21 beginning 9/80.
Massachusetts	3 through 21	- - - - -
Michigan	0 to 26	Who have not graduated from high school
Minnesota	4 to 21	Or completion of secondary program.
Mississippi	6 through 18	6 through 20 by 9/1/80. No requirement and not usual to provide classes to 3-5.
Missouri	5 through 20	Allows districts to provide programs to 3 through 4.
Montana	6 through 18	3 through 21 by 9/80. Provides for services to 0-2 after 9/1/80 under certain circumstances; 3-5 and 19-21 currently under same circumstances.
Nebraska	0-21	From date of diagnosis or notification of district; voluntary as specified by parent -- below 5.
Nevada	Between 6 and 18	Between 3 and 21 by 9/1/80. (Under 18) attendance excused when completed 12 grades. 3-5 is permissive.
New Hampshire	Between 3 and 21	- - - - -
New Jersey	5 to 21	Permissive below 5 and above 20.
New Mexico	- - - - -	- - - - -
New York	Between 5 and 21	- - - - -
North Carolina	5 through 17	0 through 4 and 18 through 21 permissive.
North Dakota	6 to 21	0 to 6 permissive.
Ohio	5-21 **	Do not actually say 5-21 is mandate.
Oklahoma	4 through 17	Except no set minimum age for visually impaired/hearing impaired.

STATE	AGES	EXCEPTIONS/CLARIFICATIONS*
Oregon	6 through 20	3-5 and 21 at local options.
Pennsylvania	6-21	Permissive below 6. Virtually all districts provide Kindergarten for 5 year olds, therefore, must provide for handicapped at 5.
Rhode Island	3-18 **	3-21 by 9/1/80 (until complete high school or reach age 21, whichever comes first).
South Carolina	Between 5 and 21	Hearing impaired 4 to 21.
South Dakota	0 through 21	- - - - -
Tennessee	4 through 21	Hearing impaired and deaf 3 through 21.
Texas	Between 3 and 21	- - - - -
Utah	5 through 21	- - - - -
Vermont	6 to 21	Or completion of high school, 3-5 as funds are available except all districts providing public Kindergarten will serve 5 year olds.
Virginia	Between 2 and 21	- - - - -
Washington	5 to 21	Pre-school permissive below 5 except if offer pre-school as a part of regular program. Every handicapped of same age shall be provided same services. Eligibility ends when goals of IEP reached, at graduation or at age 21. 3 and above at local discretion. Below 3 if multiple, gross motor, sensory, moderate or severe mental retardation.
West Virginia	Between 5 and 23	3 and 4 permissive.
Wisconsin	3 to 21	- - - - -
Wyoming	0 through 21	- - - - -

NOTE: This information was taken from Annual Program Plans submitted in accordance with P.L. 94-142. New Mexico has elected not to participate in this grant program during the current school year and, therefore, has submitted no plan.

* Many States provide for permissive services at ages below 6 and above 17. For some States this may mean that State funds can be used while, for other States, this means that services are not prohibited for these children.

** These States did not provide information in their plans as to whether the age range was to, or through, the upper age figure.

List of Local Community Resources

General

1. Physicians/Dentists
2. Day care
3. Nursery school
4. YMCA, Boy/Girl Scouts, 4-H Clubs
5. Big Brother/Sister programs
6. Single parents groups
7. Family planning organizations
8. Social Services/Welfare (goes with #9)
9. Food stamps/AFDC/WIC/WIN/Homemakers
10. Social Security - SSI and SSDI
11. PTA/PTO
12. Church (general and special classes)
13. Community organizations - Lions, Elks, Jaycees, Women's Clubs, Shriners, VFW, CAtholic Charities
14. League of Women Voters
15. Public interest law firms

Specialized

1. Public school - regular and special classes
2. Screening clinics - vision and hearing
3. Specialized clinics - CP, speech-language, OT
4. Specialized day program for handicapped
5. Parent help groups
6. Sibling groups
7. Voluntary organizations - ARC, CP, Epilepsy, LD
8. Genetic counseling

9. Crippled children program
10. Hemophilia program
11. Cystic Fibrosis program
12. Home training
13. Sheltered employment
14. Specialized recreation
15. Summer day care (general and specialized)
16. Summer residential camps (general and specialized)
17. Child Caring institutions
18. Mental Health Clinics/Centers
19. Adult day programs
20. Sheltered workshops
21. On-the-job training
22. Respite care (emergency/short term)
23. Foster care
24. Boarding homes
25. Group homes
26. Information and Referral services
27. Professional organizations - CEC

Coordinating Council for Handicapped Children
LET'S MAKE WAVES
407 S. DEARBORN STREET · Room 680 · CHICAGO, IL 60605 · (312) 939-3513

TAX SHEET

For More Information Call:
YOUR LOCAL IRS INFORMATION
SERVICE, 312 - 435-1040(Chgo.)

Written and Prepared by:
COORDINATING COUNCIL FOR HANDICAPPED CHILDREN
from material provided by Internal Revenue Service

FACTS YOU SHOULD KNOW ABOUT TAX DEDUCTIONS FOR YOUR HANDICAPPED CHILD

IF YOUR HANDICAPPED CHILD ATTENDS A SPECIAL SCHOOL OR INSTITUTION WHICH ALLEVIATES HIS MENTAL OR PHYSICAL CONDITION . . .

...You may deduct the following as "medical" expenses:

1. tuition costs
2. cost of board and room

(Revenue Ruling 58-280; Section 213-1 (e) Internal Revenue Code 1954)

3. cost of sheltered workshop
4. cost of halfway house or nursing home

(Revenue Ruling 69-499, 1969-2CB39)

IF YOUR HANDICAPPED CHILD LIVES AT HOME . . .

...You may deduct as "medical" expenses the cost of:

1. special school - if the principal purpose is to alleviate his handicap.
2. special class in a regular school - if the principal purpose is to alleviate his handicap. (Revenue Ruling 70-285)
3. special class in a parochial school - if the principal purpose is to alleviate his handicap. (Revenue Ruling 71-347)
4. tests and evaluations
5. therapy, psychiatric care, and psychological counseling
6. special instruction or training - such as lip reading, speech instruction, braille. (Revenue Ruling 68-212, Internal Revenue Code, Regulation Section 1.213-1 (e) (1) (v) (a))
7. patterning exercises (Revenue Ruling 70-170, 1970-1 CB 51)
8. medicines, drugs, and vitamins. Also special foods and beverages prescribed by a doctor (These must be in addition to your normal diet and not part of nutritional needs)
9. all medical expenses, even though the child has earned more than $1000 annual income. You may include medical expenses for a person you could claim as a dependent, except that the person had income of $1000 or more or filed a joint return. (Commerce Clearing House Explanation #2019-01).
10. tuition and tutoring fees paid for a child with a Learning Disability caused by a neurological disorder. (Revenue Ruling 78-340, Sept. 18, 1978. Reported at 42 U.S.L.W. 2190, Sept. 26, 1978.)

IF YOUR HANDICAPPED CHILD ATTENDS A SHELTERED WORKSHOP . . .

...You may deduct as "medical" expense the cost of the workshop - if the principal purpose is to alleviate his handicap. (Letter from Mortimer M. Caplin, U. S. Commissioner of Internal Revenue to Dr. Stafford L. Warren, Special Assistant, to the President for Mental Retardation, July 6, 1964)

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IF YOU INCUR TRANSPORTATION COSTS (PLANE, TRAIN, BUS, OR TAXI FARE) WITH YOUR HANDICAPPED CHILD . . .

...You may deduct them as "medical expenses" if they are incurred going to and from:

1. special schools and institutions
2. hospitals
3. doctors' offices
   R. T. Olson 23-TCM-2008, Commerce Clearing House Explanation #2019-793)

The cost of hiring a person to accompany a handicapped child who cannot travel alone to the above places is also tax deductible (Revenue Ruling 58-110).

If you provide the transportation yourself, you are allowed to deduct 9¢ per mile, parking fees and toll fees. (Rev. Proc. 74-24, C. B. 1970-2, 505)

IF YOU VISIT YOUR HANDICAPPED CHILD AT A SPECIAL SCHOOL OR INSTITUTION . . .

...You may deduct as "medical" expense transportation costs - but not meals and lodging - if medical experts deem your visit a necessary part of treatment. (Revenue Ruling 58-533)

IF YOU OR YOUR SPOUSE IS BLIND . . .

...You are allowed an extra $1000 exemption.

IF YOU ARE GAINFULLY EMPLOYED OR ACTIVELY SEEKING EMPLOYMENT . . .

...You are allowed a tax credit for child care or home care expenses during the time you work or seek employment in the amount of 20% of work related expenses.

YOUR WORK RELATED EXPENSES ARE LIMITED TO...

- $2000 per year for care of one disabled child or disabled adult
- $4000 per year for care of two or more disabled children or disabled adults

You are not allowed a tax credit for amounts paid to your dependent or your child under 19. (IRS Publication #503, Child Care and Disabled Dependent Care). You may use payments you made to relatives who are not your dependents, even if they lived in your home.

Please Note: Child Care and Disabled Dependent Care Expenses are claimed as a tax credit - not as a deduction. This means that you do not have to itemize your deductions to take advantage of this tax benefit, which reduces your tax liability dollar-for-dollar. This new provision is part of the 1976 Tax Reform Act.

PLEASE NOTE:

1. All medical deductions must exceed 3% of your total income (Internal Revenue Code, Section 213 (a) (1).
2. All medical deductions are allowed regardless of your handicapped child's age.
3. You are still allowed the full $1000 exemption whether or not your child attends a special school or institution. For tax purposes, the cost of tuition, room and board is considered a scholarship and is not taken into account in determining whether parents have provided more than half the child's support. (Revenue Rulings 61-186, 1961-2CB 64-221, 1964-2CB46).
4. Persons who are eligible for the above deductions, who have not filed them previously, may file an amended return, retroactive for the past three years.

ALLOWABLE MEDICAL DEDUCTIONS

PROFESSIONAL SERVICES

Chiropodist
Chiropractor (lic.)
Dentist
Dermatologist
Gynecologist
Neurologist
Obstetrician
Oculist
Optician
Optometrist
Orthopedist
Osteopath (lic.)
Pediatrician
Physician
Physiotherapist
Plastic Surgeon (not to beutify)
Podiatrist
Practical or other non-professional nurse for medical services only.
Psychiatrist
Psychoanalyst
Psychologist
Registered Nurse
Surgeon
Occupational Therapy

MEDICAL TREATMENTS

Acupuncture
Blood Transfusion
Diathermy
Electric Shock treatments
Healing Services
Hydrotherapy(water treatment)
Injections
Insulin treatment
Nursing
Organ transplant
Pre-natal/post natal treatment
Psychotherapy
Sterilization
Radium therapy
Ultra-violet ray treatment
Whirlpool baths
X-ray treatment

EQUIPMENT AND SUPPLIES

Abdominal supports
Air conditioner (for medical purpose)
Ambulance
Arches
Artificial teeth, eyes
Autoette (car device for handicapped person), but not for business use
Back supports
Braces
Crutches
Elastic hosiery
Eyeglasses
Flouridation unit in home
Hearing aids
Heating devices
Invalid chair
Iron lung
Orthopedic shoes
Reclining chair(prescribed)
Repair of telephone equipment(deaf)
Sacroiliac belt
Special belt
Special mattress or plywood bed boards for relief of arthritis of the spine
Splints
Truss
Wig (for med. purposes)

HOSPITAL SERVICES

Anesthetist
Hospital bills
Oxygen mask, tent
Operating Room
Vaccines
X-ray technician

LAB EXAMS & TESTS

Blood test
Cardiographs
Metabolism tests
Spinal fluid test
Sputum tests
Stool Exam
Urine Analysis
X-Rays

MEDICINES

Cost of prescriptions
Drugs
Patent Medicines
Vitamins, Tonics, Etc. (prescribed by doctor)

MISCELLANEOUS

Alcoholic inpatient care costs
Asylum
Birth control pills
Braille books
Clarinet lessons advised by dentist for treatment of tooth defects
Convalescent home - - for med. treatment
Drug treatment center/inpatient care
Installation and cost of medically prescribed equipment (seat elevator, central vacuum,etc.) minus the increased real estate value (if owned)
Kidney donor's expenses
Legal guardianship fees of mentally ill spouse, where commitment was necessary
Maintenance of special equipment
Medical insurance premiums - up to $150
Nurse's board and wages, inc.SS tax you pd.
Remedial reading for dyslexia child
Sanitarium & similar institutions
Seeing-eye dog and its maintenance
Wages of guide for blind person
Special school costs for physically &mentally handicapped children
Telephone/teletype costs for deaf person

INTRODUCING THREE BOOKS NO PARENT OR PROFESSIONAL SHOULD BE WITHOUT

HOW TO GET SERVICES BY BEING ASSERTIVE will show you how to build self confidence, improve your communication, and negotiating skills, cut red tape, and move bureaucratic mountains, and much more. Available for $4.00 plus 60¢ postage.

HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES will show you how to be an effective advocate, an effective organizer, and how to lobby, and much more. Available for $4.00 plus 60¢ postage.

THE DIRECTORY OF SERVICES FOR HANDICAPPED CHILDREN AND ADULTS is a spiral bound 311-page REDBOOK, listing 1,571 resources for the handicapped from birth through adulthood in the Chicago metropolitan area, both by disability, and alphabetically. Available for $10 plus $1.50 postage & handling.

PLEASE SEND ME:

___Copies of How to Get Services by Being Assertive ($4 each,plus 60¢post.)

___Copies of How to Organize an Effective Parent/Advocacy Group & Move Bureaucracies (At $4 each, plus 60¢ postage per book.)

___Copies of the Directory of Services for Handicapped Children & Adults at $10 each, plus $1.50 postage and handling per book.)

20% Discount available for orders of $100 or more in any combination.

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Address__________________City________State__________Zip________

RIGHTS TRAINING SESSIONS FOR FOR PARENTS AND PROFESSIONALS

Free training sessions weekly on Tuesdays & fourth Saturday of every month.* in Suite 680, at 407 S. Dearborn Street, Chicago, Illinois, 60605. (312/939-3513) Childcare is available, if requested ahead of time. Learn how to effectively represent your child so that he/she receives appropriate services. Learn how to develop an IEP that is exactly suited to his needs. Sessions are free; registration requested.

NAME______________________________PHONE______________

ADDRESS__________________CITY________STATE__________ZIP________

ATTENDANCE DATE___NO. WHO WILL ATTEND___CHILDCARE NEEDED?___NO. OF CHILDREN________

* NO TRAINING SESSIONS ARE HELD ON HOLIDAYS OR HOLIDAY WEEKENDS

WHAT'S HAPPENING? YOU'LL KNOW IF YOU RECEIVE THIS NEWSLETTER EACH MONTH. MAIL YOUR TAX DEDUCTIBLE CHECK TO CCHC. JOIN US. WE GET THINGS DONE.

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MAIL TO CCHC, 407 S. DEARBORN, ROOM 680, CHICAGO, IL 60605

UNIT VI: ADVOCACY

GOALS AND OBJECTIVES

Strategies for Effective Advocacy

Purpose:

To provide information which clarifies (a) why handicapped children and youth are in need of Allied Health advocates, and (b) the different models and strategies that can be used.

Specific Objectives:

At the conclusion of this session, participants should:

1. Be sensitive to and accept the advocacy needs of handicapped children and youth.
2. Be able to define the concept of "advocacy" as used in this workshop and be aware of other advocacy models, such as: self-advocacy, ombudsman, citizen advocacy protection and advocacy systems, and legal advocacy, depending upon the need and the context of the situation.
3. Be able to identify appropriate target group(s) with which to effectively advocate on behalf of handicapped children and youth.
4. Understand and accept the Allied Health professional's role in advocacy, whether in the schools, health programs, or other service programs.
5. Be able to identify pitfalls to effective advocacy, such as: conflict of interest; resistance to change; and discriminatory policies and practices.
6. Be sensitive to and be able to identify the needs, problems, and concerns of other health professionals, educators, and administrators regarding their roles and responsibilities in providing services for handicapped children and youth.
7. Understand and be able to implement appropriate communication strategies for dealing with other health and related services professionals, educators, and administrators when making referrals and advocating for the rights of handicapped children and youth.

General Session IV

STRATEGIES FOR EFFECTIVE ADVOCACY

Shirley Atkins, Ph.D.
Assistant Dean
School of Health Related Professions
University of Pittsburgh

and

Ethan Ellis
Deputy Director
N. J. Office of Advocacy for
the Developmentally Disabled

I. Rationale for the Allied Health Professional's Role in Advocacy

1. Health and the elevation of quality of life
2. Power and the access to power of health professionals
3. Society's respect for the Allied Health Professional's knowledge, training and contribution to saving life
4. Comprehensiveness of health care as a factor in the society

II. Advocacy Needs of Disabled Children and Youth and their Families

The advocacy needs of a child or youth with a disability, or his or her parents, grow out of specific situations and should be defined by the context of those situations. Let's look at a few:

A. Isolation - The need to talk to someone who is caring but objective about a disabling condition and its impact and implications;

B. Information - The need to identify the range of services available for a specific disability: where to get that information, how to get those services, or how to evaluate them;

C. Relevance - The need to understand how a specific service - particularly the one you provide - relates to their disability and their goals for coping with it;

D. Rights - The need to know and understand the federal and state statutes and regulations which protect their rights and entitle them to services, and how to secure these rights and entitlements in specific situations;

E. Support - The need to link up with groups who can provide them with mutual support and/or are engaged in individual and collective advocacy.

III. Advocacy Models

In recent years, advocacy on behalf of persons with disabilities has become more popular. It is now attractive both as a profession and as a pastime. This has led to a proliferation of advocacy models and confusion over definitions. Generally, the professionals try to limit what is defined as advocacy to those activities most like their own. The pasttimers do the same. These distinctions are largely lost on persons with disabilities who just want help and some helpful definition of what a prospective helper might do for them.

The effort here will be guided by those needs. Different kinds of advocacy can be defined by who does it, what they do, their goals, and who they advocate for.

Let's first sort out those activities done for individuals from those done for groups of persons with disabilities. Where these different types of advocacy activities have been given labels, they will be identified and explained.

A. Individual Advocacy

1. Provision of generic services
2. Counseling
3. Coordination of generic services - case management
4. Support - Citizen Advocacy and peer counseling
5. Lay Representation - informal and formal
6. Legal Representation - P&A Systems, Legal Services, private attorneys
7. Protective services

B. Collective Advocacy

1. Planning and administration of generic services
2. Standard setting, licensure, and code enforcement
3. Mutual support - consumer and parents group
4. Public education, attitude modification
5. Systems advocacy
6. Legislation, administrative rulemaking
7. Class action law suits

(See, "Protection and Advocacy in the Context of its Legislative History," Advocacy Systems for Persons with Developmental Disabilities, published by Research and Training Center in Mental Retardation, Texas Tech. University.)

Now let's look at some of the distinctions blurred by this typology:

C. Self-Advocacy
D. Lay Advocacy
E. Professional Advocacy
F. Legal Advocacy

IV. Natural Environments for Advocacy

A. The child and the family
B. The site at which one works
C. The personnel with whom one interacts
D. The nursery school and preschool setting
E. The school
F. The P.T.A.
G. The religious environments in the community
H. The human service organizations
I. The specific organizations to which one belongs (i.e., A.P.T.A., A.A.U.W., A.A.U.P., A.M.R.A., etc.)
J. Institutions of higher learning
K. Legislative/Regulative Bodies at local, state, and national levels.

V. Methods for Achieving Advocacy:

A. Self assessment (awareness of one's own biases, limitations and methods of expressing these: language, non-verbal behavior, avoidance, etc.)
B. Self-education (reading, personal contact, etc.)
C. Declaration of the advocacy position in all the units of life which affect you (i.e., not being willing to tolerate the "moron" joke, or the speech impediment joke)

D. Supporting affirmative action legislation as an instrument directed to the amelioration of all forms of discrimination which have human differences as a basis

E. Strengthening yourself for irrational objections to the laws and advocacy practice

F. Reminding yourself and those who work with you that people have the right to self determination (We can't "arm-chair" judge whether or not a person of small stature can become a P.T. or whether a blind man can become a medical technologist.)

G. Changing the environment to maximize the competence of handicapped individuals (physical plant, learning materials, supportive resources)

H. Observing and communicating with professional peers when they have failed to be facilitators maximizing the handicapped child's potential

I. Promoting the recognition of the unique individuality of handicapped children (Some are needle phonic others may not be, but both have the right to proper preparation.)

J. Networking for self-support (call on those at this workshop, for example)

K. Networking for change (use of referrals, inviting advocates to speak at groups in which you are a member)

L. Making those who have power responsible for advocacy (legislators, other levels of medical practitioners: dentists, doctors, etc.)

VI. Advocacy Groups and Agencies--Who They Are and How to Find Them (Also see Resource Appendix)

A. Legal Advocacy

1. Protection and Advocacy (P&A) Systems
2. Legal Services Corporation--phone book, call or write Legal Services Corp., (733 15th St., N.W., Washington, DC, 202-376-5100)
3. Other--contact State Bar Association, Protection and Advocacy Systems, State Developmental Disabilities Planning Council

B. Systems Advocacy

1. State Developmental Disabilities Planning Council--contact State Mental Retardation/Mental Health agency
2. Consumer Groups--contact state or local Association for Retarded Citizens, United Cerebral Palsy Association, Easter Seal, March of Dimes, P&A Systems
3. State Professional Societies and Associations

C. Consumer Support and Advocacy Groups

1. See A-1, B-2, above
2. Call or write American Coalition of Citizens with Disabilities, Inc., 1200 15th Street, N.W., Suite 201, Washington, DC 20005 (202) 785-4265
3. Parents groups concerned with special education--contact State Education Department or local school district
4. Independent Living Programs and Centers--contact State Vocational Rehabilitation Agency, P&A Systems.

VII. Pitfalls to Effective Advocacy

Most mistakes in advocacy result from a loss of perspective or a distortion of the advocate's role. They plague the professional advocate as often as they do the volunteer. The most serious and most common one occurs when the advocate slips out of the proper role of assistor or clarifier into the improper role of decision maker for the person with a disability. After helping a hundred parents work through in their own minds what are proper educational goals for their children's IEPs, it is easy to simply tell the hundred and first that Johnny should be reading at the fifth grade level at the end of the school year. And yet, it is a basic principle of advocacy that the person with a disability (or his or her parents) must be involved in the process to the greatest extent possible.

Let us examine some principles of effective advocacy and illustrate through example the pitfalls that yawn under the feet of the advocate who ignores them.

A. The advocate clarifies, the person with a disability decides (See above).
B. Advocacy strategies generally must be carried out by the persons with a disability or their parents. If they don't understand the strategy and feel comfortable carrying out each of the actions it requires, it won't work.
C. Strategies must evolve from and relate to specific situations. Identical strategies only work in identical situations. How many are there?
D. Children and adults with disabilities are human and prone to human orneriness and unpredictability. Your positive stereotypes about them are as self defeating as your negative ones.
E. When the child or youth has a role in the advocacy strategy, involve him or her in its development and implementation. They sometimes think independently of their parents.
F. Don't let your role as advocate conflict with your role as a professional unless you're ready to change professions. If there is a conflict, direct the person with a disability to an advocate who does not have such a conflict. If you don't know one, rethink this whole workshop.

VIII. Summary and Conclusions

1. Advocacy for the handicapped: Advocacy for a better society.
2. Advocacy for the handicapped: Preservation of your human rights.

Implementing Effective Advocacy Strategies

Purpose:

To have participants develop effective advocacy strategies for their own employment and community situations.

Specific Objectives:

At the conclusion of this session, participants should have:

1. Identified the current conditions of their personal work and community environment and recommend specific strategies for effective advocacy.
2. Identified possible strategies for dealing with pitfalls to effective advocacy, such as:
   a. conflict of interest;
   b. resistance to change; and
   c. discriminating policies and practices.
3. Developed several personal and professional strategies for expanding advocacy efforts in their own health facilities, communities and/or in their local, state, or national professional societies.

UNIT VI: ADVOCACY

RESOURCES

- The Allied Health Professional and the Rights of Handicapped Children and Youth by Shirley Atkins, University of Pittsburgh.
- Advocacy - chapter from the Advocate Resource Manual, by Nebraska Advocacy Services.
- Professionals Can Be Effective Advocates*
  *Adapted from How to Get Services by Being Assertive by the Coordinating Council for Handicapped Children.
- Advocacy is... Advocacy is not ...*
- The Role of Parent Groups.*
- Systems Change Advocacy.
- How do you Change Attitudes? from CLOSER LOOK.
- Recommended Readings on Advocacy
- Bibliography
- "A Health Advocate's Guide to the Federal Budget Process," by David F. Cavkin and Yvette Hutchin from Clearinghouse Review, Vol. XV, No. 4 (August/September 1981).

THE ALLIED HEALTH PROFESSIONAL AND THE RIGHTS OF HANDICAPPED CHILDREN AND YOUTH

By Shirley Atkins
University of Pittsburgh

Professionals who practice in the field of health and healing know the delicate balance between mind and motion, heart and hand, attitude and recovery. We call upon you for yet another measure of your wisdom, not just as it pertains to the health of individuals, but as it may bring a power of healing to our society. For surely there must be something wrong with a society which has so long procrastinated in its ability to offer those who are different the whole array of opportunities and rights common to "mainstream humanity."

I am especially fond of the manner in which Leo Buscaglia ('75) articulates the rights of disabled persons. I would summarize what he says in the following manner. Handicapped people have:

1. the right to live life in a creative, comfortable, and growth fulfilling manner;
2. a right not to have to be superior or be a super human in order to lay claim to equal opportunities of education, and work;
3. the right to be instructed concerning the nature of their condition;
4. the right to equal status in society and the family;
5. the right to offer input in the decisions which affect them and the life segments with which they are involved;
6. the right to superior education for life: affective aspects as well as academic aspects.

In what way do these rights link themselves with the health professional's practice? It would seem to me that even with my coalescence of Buscaglia's statement of rights, the health professional can find each of these rights linked to the health care delivery and advocacy for disabled children.

Let us examine the first right--the key word here is comfortable because without the essence of comfort (ease, relief from anxiety, etc.) one cannot achieve maximum and total growth. In the practice of health care the need to put the patient at ease is recognized as a primary prerequisite for effective treatment. It is obvious that if you have anxiety about a child's handicap or impairment, it is going to deter your ability to put the child at ease or give comfort. So the first task, in development of skill in advocacy of handicapped children, is for the practitioner to achieve comfort with the array of human differences presented by disabled children.

We all know that familiarity leads to comfort. So comfort may be achieved for the health practitioner as he/she reads about persons with handicaps, seeks out opportunities for personal interaction with disabled individuals, or learns vicariously through motion pictures, observations, etc.

The second statement pertains to the disabled child's right not to have to be super human. Buscaglia is talking about a right to be average as well as outstanding and the right to fail as well as succeed. As they have this right, so do you have the privilege of not having to be super human in your relationship to these children. The strong desire and need to perform well as a professional can sometimes preclude the human or humane qualities which may bring comfort to the treatment situation. Laughing at oneself and laughing at genuinely funny situations can break the barriers between administering treatment and achieving a partnership in recovery.

The second step in your preparation for advocacy is for you to have the attributes which make you uniquely you and to own these as part of your professional identity. I'm talking about a sense of humor if that's what you have, a smile, a sense of quietness, or whatever human traits make you a person.

The third right a disabled person has is the right to be instructed concerning his/her condition. You have the privilege of knowing as much as exists about the condition of the child with whom you interact, and the responsibility of seeing that the agency informs the child and those responsible for the child of the ramifications of the situation.

In many respects the fourth right is reflected in the second and third rights. It means that you may have to facilitate equal status in the family by calling in the parents and the child for progress meetings or together with the total family, you may have to assist your agency in helping a handicapped child and his/her family take a step toward greater responsibilities (for example, less time in the special classroom, more time in the regular classroom; preparation for college; readiness for courtship; readiness for employment).

The fifth right the disabled child has is the right to offer input into the decisions influencing his/her life. Not only should the child be present at your meetings with the family but, to the extent possible, the child's opinions should be solicited. This right gives you the privilege of communicating all that you may see in direct interaction with the child and his/her family and communicating the totality of your observation to all those on the health care team who work to maximize the life potential of the child.

The last right is the right to superior education for life. Buscaglia is talking about the right to academic tools for life adjustment, and the right to affective tools for life management. The latter is made up of experiential opportunities which equip the individual with coping skills for the management of fear, anxiety, frustration, and the like. This last right I see as being capsulized in the concept of hope. As the child has this right, so must you take this trait to be evidenced in you as a health practitioner. Hope is the foundation of health. Your professionalism cannot survive without it and no child can grow without it.

Hope allows for risks and every risk which is overcome marks another step down the trail of human competency.

The rights of persons with disabilities are the rights of all human beings in this society. Their rights should help us recognize and respect the whole spectrum of human differences without assigning values to those differences.

WHO DOES WHAT FOR WHOM

A Guided Tour of Advocacy for Persons With Disabilities

Ethan B. Ellis

In the 1960s and 1970s, the Courts increasingly recognized that persons with disabilities have specific rights which stem directly from those disabilities. At the same time, federal and state legislatures greatly increased the number of programs designed to serve such persons. As a result, more and more people have become active in protecting these rights and securing these service entitlements for persons with disabilities.

They have called themselves advocates and have called what they do advocacy. As this new field has become more popular, more persons have crowded under its banner and a wider range of activities have been subsumed under it. New labels like "systems advocacy" and "self advocate" have emerged in such profusion that the newcomer to the field often needs a scorecard to identify the players or the activities they are engaged in. The following is one man's attempt to provide such a scorecard. Keep in mind that some of the players still quibble over the finer points of definition and sometimes succumb to territorial jealosies. This generally occurs in any field where volunteers and professionals practice side by side as they do in advocacy and only attests to the humanness of both classes of practitioners.

In trying to make the distinctions in this field as sharp as possible, let's look at them from several angles. First, let's classify them in terms of whether they serve individuals with disabilities or groups of such individuals. Then, let's look at the different activities engaged in individual and collective advocacy. Finally, let's look at who commonly performs which kind of advocacy activity and how these roles sometimes overlap.* This may involve some repetition. Hopefully, the repetition will make the distinctions clearer.

I. Classification: Individual Versus Collective Advocacy

  A. Advocacy on behalf of individuals with disabilities

    1. Provision of generic (functional) services
    2. Counseling and support - Citizen Advocacy and Peer Counseling
    3. Coordination of generic services - case management
    4. Lay representation - informal and formal due process proceedings
    5. Legal representation - formal due process proceedings, litigation
    6. Protective services - intervention against abuse and neglect

  B. Advocacy on behalf of groups of persons with disabilities

    1. Planning and administration of generic services
    2. Mutual support
    3. Systems advocacy - administrative coordination and rulemaking, legislation
    4. Standard setting and enforcement, licensure
    5. Class action litigation.

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* In developing the following typology for the field of advocacy, the author borrowed heavily from Boggs, Elizabeth Monroe: "Protection and Advocacy in the Context of its Legislative History" in Advocacy Systems for Persons with Developmental Disabilities: Context, Components, and Resources; Texas Tech University, Lubbock.

The terms "case advocacy" and class advocacy" are sometimes used to label the two categories identified above. They are interchangeable with individual and collective advocacy, respectively.

In each category above, the types of advocacy have been arranged along a continuum beginning with those which are the least formal and ending with those which employ the most formal proceedings and enforcement measures. To some extent, the involvement of volunteer versus professional advocates parallels this continuum with the volunteers being more heavily involved in the first-listed types in each category and the professionals in those listed later. However, this distinction is frail enough to start a lot of arguments and resolve very few.

II. Definition of Advocacy Activities

Let's take a brief look at each of the activities listed and see how they've earned their practitioners' claims for inclusion under the umbrella term, advocacy.

Individual Advocacy

A. Provision of generic services

Very few of the services that a person with a disability receives are delivered in a vaccuum. Generally the service providers are linked together formally or informally and the service provided by one impacts on the way others deliver theirs. Each develops a unique understanding of the person with a disability and his or her needs. To the extent that the individual service provider uses that understanding to improve the totality of services provided, he or she is an advocate for the disabled client. The dietician who sees a patient having difficulty with a knife and fork and who suggests an occupational therapy evaluation is an advocate at the most basic level. So is the lab technician who spots a barely perceptible limp which, on examination, proves to be evidence of an undetected stroke. Both have transcended their normal professional duties to obtain better services for the persons under their care.

B. Counseling and support - Citizen Advocacy and Peer Counseling

Counseling in the generic sense of providing guidance and psychological support can be an adjunct to advocacy when it is used to help the person with a disability or parent(s) of a disabled child to clarify their goals and gather the strength to pursue them. In varying degrees of intensity, professional counselors, friends, and other professionals provide this advocacy service.

In addition, there are two programs of support which have become formalized enough to be recognized as sub fields within advocacy. The first, Citizen Advocacy, was developed to provide support to young persons and adults with mental retardation so that they can live more independently. Most Citizen Advocacy programs are sponsored by local Associations for Retarded Citizens, but an increasing number are being developed to serve other persons with developmental and related disabilities, either by volunteer agencies such as United Cerebral Palsy Associations or by the Developmental Disabilities Protection and Advocacy Systems.

These programs generally employ volunteers on a one-to-one basis who provide support and companionship to a person with a disability called a protege. The volunteer may perform other services for the protege to improve the skills he or she needs to function more independently. These may include tutoring or less formal training in eading and language arts, grooming and personal hygiene, money management, shopping and meal preparation. In some instances, the Citizen Advocate may intercede on the disabled person's behalf with community institutions and social service agencies to increase their understanding and acceptance of that person. In conflict situations, the Citizen Advocate may speak on his or her behalf as a lay advocate and some programs engage in systems advocacy to change the community response to persons with disabilities as a group.

The second, Peer Counseling, has grown out of the Independent Living movement. In this program, persons with disabilities who have succeeded in living independently share their skills and experiences in a counseling relationship with others who have recently become disabled and/or who are trying to achieve a greater degree of independence. The sophistication of this program, like that of Citizen Advocacy programs varies with the degree of training of the helping person and the complexity of the problems of the person he or she is helping. Some Peer counselors are paid and others are volunteers depending on the philosophy and/or funding level of the program in which they work.

C. Coordination of generic services - case management

Some disabling conditions require complexly interrelated services over an extended period of time. The person coordinating the delivery of these services for a particular disabled person has recently come to be called a case manager. Usually trained in social work, this person is charged with negotiating his or her client's way through an often disjointed network of human service agencies and insuring that their disparate services are somehow tailored to meet the client's very individual needs. This is a very specific advocacy role which has developed to serve persons with developmental disabilities. To some extent these same skills are used, generally over a shorter period of time, by the vocational rehabilitation counselor in coordinating the variety of services a person with a disability needs to prepare for and obtain employment.

D. Lay representation - lay advocacy

Many of the federal and state programs providing services to persons with disabilities have a variety of eligibility requirements. The denial of service under them may be appealed through a variety of due process proceedings. In addition, such proceedings may also be used by disabled persons or their parents who are dissatisfied with the services they are receiving from those programs. For example, both the Social Security System which provides supplemental or maintenance income to persons with disabilities and P.L. 94-142 which guarantees a free and appropriate education to handicapped children have such due process proceedings outlined in their implementing regulations.

In many cases, the first steps of such proceedings are designed to be informal and encourage negotiation of differences before the position of each party hardens. Still, the service provider is generally represented in those proceedings by professionals who are better versed in the services provided and the laws and regulations that govern their provision than are the persons with disabilities who receive them or their parents.

As a result, a number of groups have trained lay advocates to represent or otherwise assist in such proceedings. These persons have a specific knowledge of the statutes and regulations in a particular area of disability law and a familiarity with the professional disciplines providing the services in question. Often they are parents or disabled persons themselves who have gone through the process on their own behalf. In some cases, they are backed up by attorneys who provide guidance and/or step in when the proceedings become so formal as to require a lawyer. Many of the Developmentally Disabled P&A Systems have provided the training for and serve as backup to such groups which they refer to as Advocacy Networks.

E. Legal Representation

When such proceedings become formal or when the regulations require it, the services of an attorney are needed to obtain the appropriate services for a person with a disability or to protect his or her human and civil rights. The Protection and Advocacy Systems have been established by Congress to provide that service to persons with developmental disabilities. A number of states have expanded the P&A mandate to include persons with other disabilities. All have the capacity to bring legal action, either directly or through contract with private attorneys or legal service agencies. In some states, legal service agencies have projects which specifically serve persons with disabilities. In some others, state or local bar associations do so.

F. Protective services

Advocacy and law enforcement combine in programs which protect classes of persons who are particularly vulnerable to abuse and neglect. Begun to protect children, many such programs have expanded to cover the elderly, nursing home residents, and persons with mental retardation. Generally, they are a function of state government. Included as protective services are also those agencies which provide guardianship services for those persons who, by reason of mental incompetence or severe physical incapacity, are unable to make decisions for themselves. Like other protective services, some guardianship programs are specifically designed to serve disabled persons and others serve them if they belong to another protected class.

Collective Advocacy

A. Planning of generic services

At the governmental level, there are many services designed for nondisabled persons which play an important part in a comprehensive service network for persons with disabilities. Health care systems and income maintenance programs are but two examples. Increasingly, planners and administrators of programs which serve the disabled have interceded with these larger programs to redesign their services so that they will be more accessible to persons with disabilities and more responsive to the particular needs which arise from those disabilities. This advocacy function is largely carried out in the public and private sectors of the human services community and it employs the tools of planning and administration in its gentle persuasion. If it were not so sequestered and so gentle, it would be classified as systems advocacy (see below). Many do call it that.

B. Mutual support

Historically, the oldest advocates for persons with disabilities are the national, state and local voluntary agencies and associations formed to assist persons with specific disabilities. While these groups now provide a wide range of services and engage in a number of advocacy functions such as lobbying and bringing class action litigation, many still fulfill the purpose for which they were originally formed: to provide mutual support for persons with disabilities and/or their parents. As responsibility for services to persons with disabilities has shifted from the private to the public sector, many of the older groups have shifted their focus and many new groups have formed. For example, when services were primarily private, parents banded together to form Associations for Retarded Citizens and United Cerebral Palsy Associations. Now Parents Groups tend to form across disability lines to address the problems of special education in a particular school district or to lobby for changes in state laws. As an adjunct to these purposes, they also serve as a source of information and support for new parents of disabled children as the more traditional associations did at their inception and still do. Consumer groups of persons with disabilities perform these information and mutual support function for their members as well.

C. Systems advocacy

Systems advocacy, literally making changes in the sytem on behalf of persons with disabilities, takes many forms. They range from public education to change attitudes toward persons with disabilities to lobbying for legislation to protect old rights or establish new ones. They require equally as many skills. The greatest number of disparate functions are subsumed under this definition.

D. Class action litigation

These are legal actions brought in the name of specific individuals on behalf of a larger class of persons adversely affected by similar circumstances who will benefit by the same or similar relief. Class actions often have the powerful potential for redefining the rights of even larger groups of persons and are therefore seen as popular advocacy tools. Recent experience has shown them to be costly and time consuming to pursue and the judgements resulting from them difficult to enforce. Historically, they played a major role in establishing the rights of persons with disabilities.

E. Standard setting and licensure

The collective form of advocacy in protective services involves the setting of standards for the facilities which provide services to persons with disabilities and the licensing of the professionals who provide those services. The standard setting process is a legislative or administrative function of state or federal government which is often the target of systems advocates who seek to improve services to persons with disabilities. The enforcement of such standards is generally a function of state government which often requires monitoring by advocates to be effective.

III. Roles in Advocacy

Finally, let's look at the "who" in who does what in advocacy. This is the most slippery part of the exercise since the roles overlap considerably. Generally, there are three types of people who engage in advocacy: 1) attorneys and associated professional advocates; 2) health and human service professionals; and 3) persons with disabilities, their parents, relatives, and friends.

Lawyers obviously litigate and individual suits and class action litigation is exclusively their advocacy territory. Less obviously, they assist systems advocates by analyzing proposed legislation, administrative regulations, and formal agreements between government agencies for the provision or coordination of services. They may also act as the trainers of lay advocates.

A relatively new professional advocate in the field is the community organizer who assists consumers in designing and carrying out more effective strategies for change. This professional works almost exclusively in systems advocacy, though his or her efforts may also improve a group's capacity for information sharing and mutual support.

Health and human service professionals plan, coordinate, and deliver services to persons with disabilities. They provide supportive counseling and may be involved in standard setting and enforcement as well as various aspects of protective services depending on their profession. In addition, through their professional societies, they are active in lobbying for the general improvement of conditions for persons with disabilities. Thus they are systems advocates as well. As the relative or friend of persons with disabilities, they may assume additional advocacy roles.

Disabled consumers, their relatives, friends and interested volunteers act as counselors, and provide mutual support. They are lay advocates in due process proceedings. They take the lead in systems advocacy and fill the largest number of roles in that area.

IV. Conclusion

There seems to be ample room in the growing field of advocacy for anyone interested in persons with disabilities. It helps to know your role, both so you can use your skills more effectively and so you can avoid tripping over the other practitioners.

ADVOCACY*

Everyone has needs and desires. Some of them are practical, such as food, clothing, housing, and education. Others, such as recreation, friendship, and love, are emotional. People in our society are guaranteed the right to pursue these needs and desires. They are likewise granted various legal rights. Persons with developmental special needs have these same rights, as well as other specific rights (see module on Legal Rights for Clients).

Most rights are not self-enforcing. People must be aware of their rights, and in some cases insist on them. In complex matters, though, many people have difficulty in exercising their rights. Other persons are so impaired or disadvantaged that they cannot exercise their rights in even simple, day-to-day matters and cannot effectively represent their own interests. In these situations they need someone to speak up for them, to represent their rights and interests. This process of speaking up for another person is what advocacy is all about. And Advocacy is what this module is all about.

The concept of advocacy is by no means new. Throughout history, people have acted individually and through organizations to plead their own causes and those of others and to protect the rights and interests of persons unable to do so for themselves. In recent years, though, out of the growing concern for human and civil rights and an increasing awareness of the worth and dignity of all individuals, there has been an increase in advocacy movements for disadvantaged people. Persons with developmental special needs have benefited from advocacy. Advocacy helps make the principles of normalization work. It ensures that the rights of people with developmental special needs are not denied to them or ignored.

This module deals with the role of advocacy in the lives of persons with developmental special needs and with the nature of this advocacy--what it is, how it works, who is doing it. It also provides examples and exercises to assist the reader when he/she finds himself/herself in an advocacy role.

Definitions

Advocacy is commonly thought of as a legal process. But it usually doesn't involve lawyers or courts. Individuals, organizations, and agencies all play advocacy roles. The Center on Human Policy, a leading advocate in promoting the rights of people with disabilities, offers a very simple explanation of the term.

> "Advocacy is the independent movement of consumers and their allies to monitor and change human services."

This definition has several important components. It is "independent" meaning it is usually best done from outside of human services. "Movement" implies a goal orientation. "Consumers" are the people directly affected, and it only makes sense that they play a key role in promoting changes that likewise affect them. "Allies" include family, friends and professionals who are willing to share at a gut level, the consumer's anger, sense of injustice, and commitment to change.

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*Chapter from The Advocate Resource Manual, developed by Nebraska Advocacy Services, Lincoln, Nebraska.

There are several different types of advocacy which play an important role in the lives of people with developmental disabilities. The following are some of the most common types.

1. Self-advocacy refers to an individual speaking for himself/herself. This is the most basic and desirable form of advocacy. Every effort should be made to assist individuals to speak for themselves whenever possible. For example, a person should say for himself/herself, "You gave me the wrong change."

2. Citizen advocacy is a concerned volunteer representing the interests of a friend with a developmental special need. The volunteer is recruited, screened, matched, and supported by a citizen advocacy office. For example, the citizen advocate can say, "My friend has been on the waiting list for your program too long. What can you do about it?"

3. Systems advocacy is a process of bringing about changes in social and political systems that will make agencies and institutions more responsive to the needs of people with disabilities. It may be done by paid agency personnel, trainers, paralegals, organizations formed by consumers, parents and just about anyone who is concerned about the rights and interests of people with disabilities. For example, a person acting as a systems advocate may say, "My client appeals your decision to reduce his SSI benefits," or "My client isn't getting the help she needs from your agency."

4. Legal advocacy is an attorney representing a client in litigation, legal proceedings, or other legal matters. For example, the legal advocate might say, "I would like to file a writ of habeas corpus on behalf of my client." It may also involve court litigation on behalf of whole classes of people to remedy systemwide problems. "Rights to education" and "right to treatment" lawsuits are examples of class action legal advocacy.

5. Legislative advocacy is the reform of laws, rules, and regulations on behalf of people with disabilities. Involvement in the legislative process ranges from writing letters to public lobbying. A legislative advocate may say, "The passage of this law will enable people with disabilities to vote in neighborhood polling places and will encourage election commissioners to make them accessible to the entire public."

Advocacy is more than just speaking for another in order to bring about changes or to overcome barriers so that human needs and desires can be met. Speaking for another is often routine, but it can also be intense and cause disruptions. In general, advocacy occurs at the following levels:

1. Most advocacy occurs at a nonintrusive level. It is advocacy that seeks only to secure equity, due process, or what is fair and just for all people. It might involve giving information, or explaining

or interpreting a problem. This kind of advocacy should not be disturbing to the social order. For example, a care-giver informs the municipal bus company that a large facility for handicapped persons has opened on an existing bus route but that there is no bus stop near the facility. He/she requests that a bus stop be established nearby for the large number of residents who will use the bus daily.

2. The second level of advocacy is characterized as intrusive on the social order. It seeks compensatory treatment or justice. Advocacy at this level is seeking special consideration that requires some change and disruption. For example, children with mental retardation need more, not less, education than normal children. All agencies serving persons with developmental special needs may pressure the bus company to give a special discount to persons with handicaps. Since they have less money and must depend on public transportation, they should have to pay less. This will require that the company risk losing revenue.

3. The final and most intense level of advocacy is termed "disruptive." Advocacy seldom occurs at this level, but when it does, it seeks strong corrective action to right previous wrongs. It causes major changes in social order and creates disruption for many people. Class action litigation is often at the disruptive level, but some personal advocacy can also occur at this level.

A coalition of groups representing handicapped persons, for example, might sue the municipal transportation district to put lifts on every bus. This would make the buses accessible to the handicapped, but it might also mean fewer buses, money shifted from other programs to remodel buses, unemployed bus drivers, and it might lead to higher bus fares and taxes.

Regardless of the type of advocacy or at what level it occurs, three conditions must be met for the advocacy to be successful.

1. Strong Commitment. There are many ways of helping people. One way is to impose what you think is "best for the client." This is the typical approach of bureaucracies, especially of those human service systems that employ large numbers of professionals.

   Another way of "helping" people is through charity. We use charity to provide relief of suffering and to express compassion. But there are problems with charity: charity often creates dependency by the victim; charity also communicates pity rather than sharing anger; charity can romanticize the victim as a "holy innocent," "angel," or "pathetic soul" rather than treating the victim as an equal, as a friend; charity sometimes relieves suffering but usually does not alter the conditions that create the hardships.

   A third way of helping people is to become an ally. These are the qualities of an ally as compared to those of the "charitable" person.*

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* Obviously, we are not proposing that the ally and charitable person are always so very opposite or that people actually fulfill either role in exactly the manner presented here. Rather, our purpose is simply to suggest the basic qualities of these two types of "helpers."

- The charitable person keeps the victim dependent and creates or maintains the structures of dependency.
- The ally will identify and help to free the victim from dependency.
- The charitable person does not alter the victim's persistent need for help. The victim must depend on the continued good will of the charitable.
- The ally helps the oppressed person become independent and self reliant.
- The charitable person has his or her own view of what the victim must feel.
- The ally understands the victim's experiences through the victim's own words.
- The charitable person pities the victim.
- The ally treats the victim as an ally in change. The ally does not pity the victim but rather shares an anger about victimizing circumstances.
- The charitable person thinks the victim's suffering comes from the result of accident or fate or some fault within the victim.
- The ally blames social forces as the cause of the victim's oppression.
- The charitable person expects the victim to change.
- The ally works with the victim. The ally takes mutual risks and experiences change also.
- The charitable person has a plan for the victim. The victim is not a peer. The charitable person must be thanked.
- The ally and victim strategize together, mutually.
- The charitable person has easy access to the bureaucracies.
- The ally has little access to the bureaucracy because the ally is a threat to the person with power.
- The charitable person maintains friendships with the officials who, whether purposely or inadvertently, create the circumstances of victimization.
- The ally cannot maintain a close relationship with the victimizer.

2. Variety of Skills. Second, an advocate must have a variety of skills in order to carry out advocacy strategies. The most important are assertive skills that facilitate communication and action. The ability to solve problems, knowledge of resources, and an understanding of the needs of persons with developmental special needs are also important.

3. Legitimacy. Finally a certain degree of legitimacy is required when speaking up for another. Sometimes this legitimacy is acquired through a legal basis, such as that of an attorney, parent, legal guardian, or case manager. The approval of the person in need also serves to legitimize the advocate. Legitimacy also means the right to speak for another's interests. For example, the president of a company would not be seen as a legitimate spokesman for the workers on the assembly line. Advocates must share the interests of the persons for whom they are speaking.

Let's now look at how advocacy works. Although much depends on the specific situation, there are some common elements in advocacy processes and some general guidelines that can help a person be a more effective advocate.

Advocacy can be viewed as having six primary elements:

1. Client: a person or group of persons who need someone to speak with them or for them.

2. Issue: a specific issue, problem, injury, or barrier that the client needs assistance to change or overcome.

3. Target: an individual, agency, organization, or source that can provide the remedy to the problem or redress for the injury, or that can remove the barrier. The target may or may not be aware of the problem. In any case, without intervention the problem will remain.

4. Advocate: a person or group of persons who can and will act for client's best interests. There must be a minimum of conflict between the interests of the clients and the other interests affecting the advocate. The advocate may be the same as the client.

5. Outcome: a desired solution to the issue.

6. Action: a strategy that the advocate can use against the target that will lead to the desired outcome for the client.

With these six elements in mind, let's look at the steps one might follow when acting in an advocacy role.

Steps in Advocacy

1. Awareness. You must first recognize that a problem exists. This awareness often develops from observing what is missing in the lives of persons with developmental special needs. Listening carefully to what clients are asking for is another good way to become aware of what should be.

   There is no set pattern for initiating advocacy programs, since so much depends on the advocacy level, the desired outcome, the skill of the advocate, and the general circumstances of the day. There is, however, a series of standard questions that can serve as a general outline and that offers the best possibility of success.

What is being suggested is that before you become involved in confusing peoples' lives (especially your own), some forethought might be beneficial.

2. Commitment: Awareness has to be followed by a commitment to do something about the problem. The first question that must be answered is, "Are you so confronted by this need that you want to get involved personally?" Then, "Are you the right person? Could this person speak up for himself/herself? Is there someone more appropriate than you--the parent, guardian, or caseworker? Do you have any other interests that might conflict with those of the person in need? What will be the costs to you in time and money? Will there be some other human costs that you will be willing to pay?"

3. Information. Before moving on, homework is necessary. You must gather all the relevant information about the problem. What is the specific issue? Why does this problem persist? What is the desired solution? Who can do something about it? What are the relevant laws, regulations, policies? Who determines them? What are the alternative solutions? What has been tried in the past? If you fail, what happens to the person you are speaking for? Without accurate and sufficient information, the best of intentions and strongest commitment will be of little value.

Some other questions: Where do you get information? From the client, parents, service providers, agencies, consumer groups, attorneys, other advocacy agencies! How do you get it? Ask, write, interview, telephone, read! What are your resources and who are your allies? Who is against you?

4. Skills and Strategy. You've now identified the problem, the desired solution, and the parties involved. What approach should now be used? What skills are required to carry it out?

   In most instances the approach that is personal, simple, direct, and uncontroversial is the best. This is particularly true at the non-intrusive level of advocacy. Sometimes a letter, telephone call, or conference will be adequate where issues are fairly clear. Other issues might require group activities, such as letter-writing or media campaigns, public hearings, and demonstrations. The best approach might be low-keyed and informal, such as an admission and discharge hearing in a court of law. The type of approach depends on the type of issue, the degree of resistance, and the level of change desired. In any case, it should be the one that has the best chance of accomplishing the goal the advocate is after.

   A skill that is important is the ability to communicate clearly, assertively, and persistently. The ability to persuade, convince, negotiate, and compromise is also often important in effective advocacy. Probably the most important skill is the ability to recognize your own limitations and get help when you need it. The best strategy might be to find a more effective advocate.

5. Action. When we talk about action, we mean planned activities that will lead to social change. Action causes long-term change in the structure of human service systems, in human service policies and practices, and most importantly, in how people think about problems. So actions can be oriented toward structural change, policy change, or educational change.

   But not everything that people do can be considered "action." We should not consider charity a form of action, for example, because charity does not lead to change, whether through structure, policy, or education. Most forms of clinical assistance to individual children are not "actions" in the sense that we have used that term. Much of what people do in response to problems and issues such as labelling, poor service, no service, and institutional abuse, can be characterized as "relief of human suffering." When we see people suffering, we try to respond humanly, with warmth, affection, understanding, and commitment; we respond personally to the individual people who have experienced suffering. Such a human response is both necessary and morally right, but this individual response is not action.

   Organizers cannot afford to ignore human suffering. In fact, we need to develop close friendships with people who have suffered if we are to accurately work toward solving their needs. But "action" means planning activities that lead to basic changes in how people think and in how organizations operate. Action is a long-range or more permanent way of relieving human suffering. It attempts to alleviate or alter the conditions that cause human suffering. We'll talk about different action strategies in the next chapter.

6. Monitor and Evaluation. Follow up and evaluation are also important aspects of an advocacy plan. Backsliding is common for persons with disabilities. Victories are not final until programs are operational. You need to know not only when the problem is solved, but whether it is going to stay solved, amd tp wjat degree/

PROFESSIONALS CAN BE EFFECTIVE ADVOCATES *

By Janet Sullivan,
Social Worker

Being a "professional" does not have to mean that one serves first the interests at one's agency or school, and only secondarily, one's clients. Many professionals view themselves as advocates for their clients first, and employees of a school or agency second. These persons are "professional advocates."

As I discovered, many special education children were being placed exclusively on the grounds of intelligence testing; consequently, some, whose problems were not not uncovered by psychological testing were in need of services which were not provided (problem recognition). I checked this situation with my co-social worker and found that it existed in other schools (concurrence on the problem). Together, we talked with many school persons and parents at all levels and found many of them equally concerned and willing to seek some improved process for placing special education children (broadening the base of concern). We talked with our district superintendent and secured permission to survey the district's special education classes (developing statistical proof of need for change). The results of the survey were presented to the principals in the district (broadening the base of support for change).

By this time, we felt that there was strong support for movement on the problem; therefore, we organized and conducted a workshop on special education procedures with the District's Administrators, Psychologists, Nurses, Speech Clinicians, Social Workers and representatives of other disciplines servicing the schools (educating involved persons about possible new directions). At the workshop everyone was encouraged to give their ideas about improving services to special education children (establishing a democratic method of solution-finding). The idea of staffing children into placements emerged as a common goal (concurrence on a solution). A recommendation was made at the workshop that a multi-disciplinary committee be formed to develop staffing procedures for placing special education children (formalizing a problem-solving process). This committee was established by the Social Workers with the permission of the District Superintendent (acting immediately on the suggestion). It continued to meet until a staffing policy was written and implemented in the district, (perserving until solution implementation occurred).

Organization principles which undergirded this successful action:

1. Establishing clear open communication and mutual support between the two Social Workers serving the district. If there had been competition or criticism between persons of the same discipline, they would not have moved beyond themselves to effect any significant changes in the schools.

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* Adapted from How to Get Services By Being Assertive by the Coordinating Council for Handicapped Children.

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2. Concurring on the problem area. The Social Workers checked with others before initiating action in order to insure common recognition of the problem and support for change.

3. Broadening the base of concern. Before moving to a solution (which might not meet with wide-spread support), the Social Workers talked with many persons, thus building concern.

4. Developing statistical proof of the need for change. The Social Workers documented the need for an improved placement procedure to influence those who might still question the need for change.

5. Educating persons regarding possible new directions. Sensing a readiness for action, the Social Workers developed a means of bringing awareness to school personnel about various ways of solving the problem.

6. Establishing a democratic base for solution finding. By allowing input for solutions, the Social Workers built enthusiasm and commitment to solution finding and solution implementation.

7. Concurring on a solution. Through skillful group work, agreement upon a solution was secured before the workshop dispersed.

8. Formalizing a problem solving process. Through skillful organizing, a formal means of implementing a solution was agreed upon before the workshop dispersed.

9. Acting immediately on a suggestion. Before enthusiasm waned, the Social Workers moved to establish the suggested committee.

10. Persevering until solution implementation occurred. The Social Workers became group workers in the committee to facilitate movement through a maze of personal and professional concerns toward solution implementation.

A key word in this whole process was flexibility, both in the role of the Social Worker and in the strategizing. As is apparent, the Social Worker moved from a position of case worker to researcher to organizer to group worker. The Social Worker maintained openness to advice from persons at all levels and was willing to change direction when a proposed strategy was denied or thought unwise.

By utilizing knowledge of organizing principles, forming a close coalition with co-workers and constantly communicating with and supporting the administrator, the school Social Worker was able to move from a position of problem-recognition to a position of influencing policy-making. The process was long, taking almost four years, but the effect was improvement in services to the special education children in her district which included twenty-seven schools and eleven thousand, five-hundred children.

This type of service can be and has been given by School Social Workers who take seriously their opportunity and obligation to influence decision-making processes for the betterment of children.

How can parents help professionals become effective advocates? Janet Sullivan advises as follows:

Professional advocates frequently need support in order to effect changes in their agencies or schools. Parents can provide this by:

1. Attending meetings that a professional advocate organizes
2. Testifying for or writing letters for the advocate if his/her position is even called into question, and
3. Maintaining a regular exchange of information with a professional advocate to be constantly aware of the occurances within the agency.

The most significant changes occur in bureaucracies when a committed group of persons, from within and also outside of the bureaucracy, form a coalition to effect positive changes. Professional advocates need parents and consumers, and parents and consumers need professionals.

ADVOCACY IS ...
ADVOCACY IS NOT ...

ADVOCACY IS:

1. helping parents help themselves.
2. building confidence so parents are able to help themselves.
3. supporting efforts towards independence.
4. providing necessary tools for appropriate decisions and appropriate action.
5. informing parents of their rights.
6. helping parents get their rights.
7. analyzing a problem and pinpointing areas of responsibility.
8. stating options available to resolve a problem.
9. providing technical assistance and training.
10. providing assistance in locating appropriate services.
11. referring to appropriate agencies.
12. lobbying for necessary legislation.
13. agitating to get legislation implemented.
14. organizing for change.
15. initiating new services.
16. investigating grievances.
17. following up on complaints.
18. going to court when other avenues have failed to get results.
19. bringing parents and groups together for mutual support and action
20. advocating and/or interceding on behalf of parents only when they are unable to help themselves.
21. a partnership with parents, with mutual sharing of information, tasks, and action.

ADVOCACY IS NOT:

1. taking over a parent's life (or problem) and making all decisions for him/her.
2. squelching efforts of self-help.
3. reinforcing feelings of helplessness and dependence.
4. keeping parents in the dark while doing everything for them.
5. keeping parents uninformed about their rights, so they will have to rely on the advocate for everything.
6. discouraging parents from becoming activists.
7. making excuses for unavailability or inadequacy of services.
8. making decisions for parents.
9. controlling parents.
10. persuading parents to accept "make do" services
11. closing the door to parents because "there's nothing I can do to help."
12. keeping "hands off" of politics.
13. accepting the status quo when legislation is not implemented.
14. seeking individual solutions to group problems.
15. accepting unavailability and inadequacy of services.
16. denying existence of problems reported.
17. dropping a complaint after initial contact.
18. filing a lawsuit as the first approach to a problem.
19. working only with individuals when others share a mutual problem.
20. interceding on behalf of parents who can help themselves.
21. a parent/child relationship.

> "I sometimes feel so alone as a parent. And I feel so overwhelmed when I'm dealing with bureaucracies. Am I the only parent who's going through this?"

Local parent groups can assist parents cope with their concerns and problems in dealing with their handicapped children. Additionally, they can help parents become assertive by providing the information and support they need to obtain services for their children.

A PARENT GROUP CAN:

1. Let parents know they are not alone with the problems they are experiencing in getting services for their child.
2. Inform them of their rights under the Education for All Handicapped Children Act (P.L. 94-142) and Section 504 of the Rehabilitation Act of 1973.
3. Help them prepare for a staffing, IEP meeting, due process hearing, and other special education meetings.
4. Help them rehearse their presentations when negotiating for services for their child.
5. Provide support at staffings, IEP meetings, Due Process Hearings, and other special education meetings.
6. Help them lobby for more services, when the service their child needs does not exist.
7. Provide the emotional support and self-confidence they need to be effectively assertive and obtain their rights.
8. Help them file complaints with the U.S. Department of Education, the U.S. Office of Civil Rights, when services required by P.L. 94-142 and Section 504 are not being provided; or there is evidence that these laws are being violated in any way.
9. Negotiate with bureaucracies to rectify problems shared by the group.
10. Provide opportunities to share experiences, coping skills, negotiating skills and advocacy skills with other parents.
11. Organize and participate in coalitions to reach mutual goals.

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* Adapted from How To Get Services by Being Assertive by the Coordinating Council for Handicapped Children.

PARENTS CAN BECOME INVOLVED IN A PARENT GROUP AND/OR MEET OTHER PARENTS BY:

1. Contacting your local chapter of the:

    a. Association for Retarded Citizens
    b. Association for Citizens with Learning Disabilities
    c. Parents of The Hearing Imparied
    d. Parents of the Blind
    e. United Cerebral Palsy
    f. Spina Bifida Association
    g. Society for Autistic Children
    h. National Alliance for the Mentally Ill

For names and addresses of these parent groups:

    a. Consult the Appendix
    b. Contact CLOSER LOOK, BOX 1492, Washington, D.C. 20013

If there are no appropriate parent organizations in your area, ORGANIZE ONE. Follow steps outlined in HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, published by The Coordinating Council for Handicapped Children, 407 S. Dearborn St., Room 1075, Chicago, Ill., 60605.

SYSTEMS CHANGE ADVOCACY

By Marie L. Moore

Advocacy is defined as insuring disabled persons their rights to appropriate services. The process of advocacy includes finding, accessing, and developing such services at the time and in the place they are needed.

The advocacy process is especially difficult, however, when the needs are multiple. And it is particularly acute when families of disabled persons are from low-income and minority groups.

The United Cerebral Palsy Association's National Advocacy Project, launched in July, 1972, under a grant from HEW, set out to develop and monitor models of advocacy in UCP affiliates. Inherent in each model has been the establishment of an advocacy advisory council, composed of consumers, volunteers, and professionals, and the employment of an advocacy coordinator. Together, they work across-the-board in affiliate programs and in the community, intervening on behalf of persons with developmental disabilities. Intervention here means bringing about changes that remedy the problems of not just one person, but all persons in the present and future who may have similar problems.

Class advocacy has included the following approaches: 1) Initiating, influencing, and monitoring legislation affecting the developmentally disabled; 2) Using a systems analysis approach, identifying services needed and/or changes sought in the service delivery system from the consumer's perspective; 3) Initiating, influencing, and assisting in the development of new services; and 4) Promoting the active involvement of a diversity of consumers (disabled adults and parents of disabled children) in the planning, policy-making, and monitoring of services at state, county, and local levels.

Other approaches used in class advocacy include: 5) Providing technical assistance to established consumer action groups in the use of appeal procedures, the development of action strategies, and similar activities; and 6) Using community organization processes to develop better communication and cooperation among agencies, organizations, and consumer groups involved in community planning.

Case advocacy approaches have included: 1) Providing information, training, and technical assistance to case management and personnel working for UCP affiliates and other agencies in order to expand their advocacy role and function; 2) Conducting an ombudsman program for a disabled person following the report of a grievance, by investigating, interceding, or initiating action on his/her behalf; and 3) Locating appropriate legal services for consumers or groups of consumers, and providing information that will assist legal service professionals in negotiation or litigation.

In each model location, specific target populations have been identified. These have included very young parents and their children, persons from ethnic minority groups, persons residing in state institutions, and those separated from services because of location in rural, inner city, or other isolated areas.

Initially three model sites were selected. These were New York State, San Mateo and Santa Clara Counties in California, and Milwaukee, Wisconsin. Three replication sites were then chosen: Illinois, Rhode Island, and the Greater Kansas City area. The UCP affiliates in these areas represent diverse geographic and population profiles, varying patterns of service delivery and availability, and unique patterns of programming services for the disabled.

Projects Result in Many Changes

Various systems changes have resulted from UCP involvement in these project sites. For example, project efforts in San Mateo and Santa Clara Counties resulted in the establishment of a parent coalition group - Parents for Improved Community Services (PICS). This group was originally organized to address a grievance involving the exclusion of one severely disabled child in one county school system. However, it was necessary for the parent group to use a state statute which mandated a grievance procedure that had never been detailed, much less implemented.

With the assistance of the advocacy coordinator, the parent group designed a grievance procedure which is now considered a model for the entire state of California. Under this statute and using this appeal process, PICS was able to win this case, and obtain educational programming not only for the child in question, but also for 30 other children in the county. The parent group continues to monitor the quality of educational services for these 30 children, and counsel other providers of services as well.

Another example of systems change occurred in New York State, where volunteers, consumers, and UCP staff organized a statewide citizens' group to develop legislative proposals and communicate with their legislative representatives regarding the needs of the developmentally disabled. Project efforts have also facilitated new programs for disabled children in rural areas of the state and alternative living arrangements for former residents of state institutions.

In Milwaukee, project efforts included a follow-up survey of high risk infants in 250 families, most of whose cases were not followed after discharge from the Milwaukee County High Risk Infant Nursery. Findings from this survey resulted in county and state funds to improve follow-up services by the High Risk Nursery.

In addition, through information gathered in the project's ombudsman program, a grant was written and state funds obtained for legal services for the developmentally disabled. These services are currently being offered through Milwaukee Legal Services.

As a voluntary agency conducting an advocacy project in several locations throughout the country, UCPA has found that advocacy, in order to be effective, requires linkage of many advocacy systems. Advocacy is a process which reaches and teaches consumers, works to change the service delivery systems when necessary, and cements the relationship between persons who are disabled, their families, and the agencies mandated or committed to provide services. This process requires the help and input of all concerned.

ADVOCACY PROGRAMS FOR THE DISABLED

Type	Purpose	Responsible Organization
Case Advocacy		
A. Citizen Advocate	A. One-to-one relationship between a capable volunteer and a person who is disabled in which the volunteer advocates for the rights and interests of the other, and provides practical or emotional reinforcement for him.	A. Citizen Advocacy Board operated by a private association or agency.
B. Ombudsman	B. One who acts as an advocate for a disabled individual following the report of a grievance, by investigating, interceding or initiating action on his/her behalf.	B. Private - Advocacy Council or Committee operated by a private organization or association. Public - State Human Rights Commission.
C. Legal Advocate	C. One who represents a person in the litigation or legal negotiation process when rights are threatened or violated.	C. None, unless in an agency setting.
D. Case Manager Advocate	D. One who assists the individual in information, referral, follow-along services, and serves as an advocate when there are barriers to the service delivery system.	D. Public or private agencies.
E. Protective Services	E. A service mandated by legislation which provides guardianship, trusteeship - and other advocacy services.	E. State government board or council.

ADVOCACY PROGRAMS FOR THE DISABLED

Type	Purpose	Responsible Organization
Class Advocacy		
A. Legislative Advocacy	A. Using the legislative process to mandate change in the social system in order to secure the rights of the disabled.	A. Representatives of consumer organizations at local, state, and national levels.
B. Community Organization Advocacy	B. Using the community organization process to develop better communication among agencies serving the disabled; to assist in the development of cooperative or coalition efforts on behalf of the disabled by public and private providers of service, and by consumers.	B. Community or statewide planning groups, or consumer advocate groups whose membership includes consumers or consumer representatives.
C. Program Brokerage	C. Service development and program expansion by eliminating barriers which obstruct program development, and combining resources.	C. Consumer representative organization working in cooperation with governmental and private agencies.
D. Protective Services	D. A service mandated by legislation which provides guardianship, trusteeship, and other advocacy services.	D. State government board or council.
E. Consumer Action Advocacy	E. Groups of parents or adults who are disabled that act as pressure groups or influencing groups and advocate for desired change.	E. Independent organizations; groups associated with consumer representative organizations.

INFORMATION FROM . . . .

CLOSER LOOK

A Project of the Parents' Campaign for Handicapped Children and Youth

Box 1492
Washington, D.C. 20013

HOW DO YOU CHANGE ATTITUDES?

Attitudes toward disabled people have been around a long time — unfortunately, mostly based on ignorance and lack of experience. As we get to know each other better, old awkward and negative feelings will change. In the meantime, it helps to know where to turn for information on how disabled people can and do get along in the world, on their own — with adaptations and adjustments that can help them live fully.

Most disability related national organizations have educational literature and good suggestions that can help make mainstreaming work for disabled people. Parent groups, too, have long been involved in helping to eliminate fear and ignorance concerning specific disabilities. In addition, several national groups dedicate their entire effort to educating society to the abilities and needs of people with disabilities. The following have materials that can help to change attitudes and heighten awareness of what disabilities are all about.

CENTER ON HUMAN POLICY
Syracuse University
216 Ostrom Avenue
Syracuse, New York 13210

This center is an advocacy and research organization involved in the national movement to insure the rights of people with disabilities. Write for their listing of publications and slide shows.

COUNCIL FOR EXCEPTIONAL CHILDREN
1920 Association Drive
Reston, Virginia 22091

Teachers and other professionals (and parents, too) who work with handicapped children may turn to this organization for publications, computer literature searches, and topical bibliographies, including one on attitudes toward handicapped persons. A new workshop manual called EVERYBODY COUNTS! can be used as a teaching tool for awareness programs for schools and other groups.

DISABILITY INFORMATION CENTER
University of Southern Maine
246 Deering Avenue
Portland, Maine 04102

This center stems from a 1977 update of a study of the needs of disabled people in Maine. As a result of the literature search, an extensive collection of publications exists and may be tapped. A bibliography of these materials, THE DISABLED AND RELATED NEEDS AREAS, is available. A film index, DISABILITY ATTITUDES, is also available for a small fee.

HANDICAPPED LEARNER MATERIALS DISTRIBUTION CENTER
Audio-Visual Center
Indiana University
Bloomington, Indiana 47405

Films, kits, games, and adaptive devices may be borrowed from this center. Films are available on a loan basis, with the borrower paying return postage. Eligibility requirements and a materials catalog will be sent upon request.

MAINSTREAM, INC.
1200 15th Street, N.W.
Washington, D.C. 20005

With employment, education, and other civil rights of handicapped people as its aim, Mainstream conducts conferences nationally and operates other information programs on affirmative action for disabled people. Their toll-free hotline, 800-424-8089, concentrates on federal laws affecting disabled people, especially Sections 503 and 504 of the 1973 Rehabilitation Act. Write for their publications list and for subscription information for their bimonthly newsletter, IN THE MAINSTREAM.

THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED
1111 20th Street, N.W.
Washington, D.C. 20210

With job training and employment for disabled people as their first concern, PCEH strives to create greater community acceptance of persons with special needs. A publications list and film list are available — also a monthly magazine, DISABLED USA.

REHABFILM
International Rehabilitation Film Review Library
20 West 40th Street
New York, New York 10018

The library's collection of films may be rented or purchased by schools, health organizations, and hospitals for training and public awareness purposes. They publish INTERNATIONAL REHABILITATION FILM REVIEW CATALOGUE and the REHABFILM newsletter, which is devoted to the media and handicapped persons.

REGIONAL REHABILITATION RESEARCH INSTITUTE ON ATTITUDINAL, LEGAL, AND LEISURE BARRIERS
George Washington University
1828 L Street, N.W., Suite 704
Washington, D.C. 20036

The institute's research activities have resulted in a lively series of booklets, each focusing on a different set of attitudinal barriers. Materials are produced for both rehabilitation professionals and for the general public. Their free publications list includes ATTITUDES AND DISABILITY: A SELECTED ANNOTATED BIBLIOGRAPHY, 1975-77.

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RECOMMENDED READINGS ON ADVOCACY

Advocacy for the Mentally Retarded-Book 1 Community Organization, Book 2 Strategies for Problem Solving, Book 3, Advocacy for the Mentally Retarded
Bernstein, Jack
Clarke, Brenda
Collins, Leslie

Three books with practical information on affecting change at various societal and governmental levels, for persons who are mentally retarded. Book 1 provides basic information on how to establish an effective advocacy committee to advocate for persons who are mentally retarded. Book 2 contains helpful strategies in advocating for persons who are mentally retarded. Book 3 provides technical information necessary to mount a public relations campaign based on local achievements and problems. 25, 27, and 44 pp.

An Advocacy Manual for Parents of Handicapped Children
McCraven, Carol

A practical guide for parents which explains a variety of benefits available for handicapped children, including information on social security, vocational rehabilitation, training, and education services. Additionally, the book describes methods by which to assure that the state is providing the services it should. 46 pp.

Advocacy Systems for Persons with Developmental Disabilities
Baucom, Linda; Bernsberg, Gerard

Consists of combined proceedings and five issue papers on the concept of advocacy including legislative history and the planning and evaluation of advocacy systems. Various components of an effective protection and advocacy system are discussed including legal, citizen, case management, and systems advocacy. 279 pp.

Let Our Children Go
Biklen, Douglas

Describes how parents of children with disabilities, and their allies, can fight for their own needs and rights. Advocacy means moving bureaucracies. The basic steps to successful organizing.

Thinking, Learning, Doing Advocacy
Dickman, Irving R.

Explains the work done by the UCP National Advocacy Project, and the strategies that were implemented in changing various systems to be more responsive to the needs of persons with developmental disabilities. 128 pp.

Negotiation: A Tool for Change
Taylor, Steven

A paper that is designed to enable consumers, parents, and advocates to negotiate effectively. Especially useful when two groups with conflicting interests meet to discuss the issues between them. It introduces ideas in the following areas: approaches, preparation strategies for effective negotiation and follow up.

Planning Effective Advocacy Programs
American Coalition of Citizens with Disabilities Bowe, Frank and Williams, John

This book offers some guidelines for enhancing the capabilities of existing organizations and ensuring the effectiveness of new ones. The goal in publishing this book is to help disabled people throughout the nation to help themselves more, and with less frustration, through the creation of truly successful advocacy programs. 61 pp.

Advocacy - assertiveness - for parents
Parents Speak Out Turnbull, H. Rutherford III & Turnbull, Ann P.

This book is about professional who are parents. It is for professionals, both those who are and are not parents, and for parents who find that the average professional seldom sees their children and their problems from their point of view. The problem confronted is the presence of a handicapped child or adult in the family of the professional. The reactions discussed are personal, the people are real as well as their difficulties. 210 pp.

Advancing Your Citizenship: An Advocacy Manual for Persons With Disabilities Crosson, Anita; Browning, Philip; Kramps, Robert E.

The purpose of this manual is to assist disabled people and their advocates in further exercising their rights under the law. The first section introduces the reader to the three major pieces of federal legislation pertaining to handicapped individuals. The second section overviews specific mechanisms which can be used in implementing these rights, while the final section is a demonstration of the application of these rights and mechanisms.

How to Get Services by Being Assertive Coordinating Council for Handicapped Children

The contents of this handbook are based on thousands of calls, letters, and personal contacts with parents of handicapped children during the Coordinating Council's ten-year existence. The assertiveness training exercise and other techniques described in this book were developed--and used successfully by the Coordinating Council in direct response to these parent complaints.

ALLIED HEALTH CHILD-FIND AND ADVOCACY PROJECT

ANNOTATED BIBLIOGRAPHY

Attitudes and Feelings

Simon, S., et. al., Values Clarification. New York: A & W Visual Library, 1978.

A book filled with exercises designed to help its readers identify hidden and overt feelings. A good tool for developing various simulations.

General

President's Committee on Employment of the Handicapped: A Handbook on the Legal Rights of Handicapped People, Washington, DC.

This is a pamphlet which covers general legislation on architectual barriers, benefits, civil rights, education, employment, hospitals, housing insurance; etc. Material is presented in factual abbreviated manner.

Law

Meyen, E., Basic Readings in the Study of Exceptional Children and Youth. Denver: Love Publishing Co., 1979.

Textbook which offers clear and simple explanation of P.L. 94-142 as it involves concepts like L.R.E. and I.P.E. and Mainstreaming.

Parent

Buscaglia, L., The Disabled and Their Parents: A Counseling Challenge. Thorofare, N.J.: Charles B. Slack, Inc., 1975.

A beautiful book written in enchanting "Buscaglian" language and useful to anyone working on any level with the disabled and their families.

Seligman, M., Strategies for Helping Parents of Exceptional Children. New York: MacMillan Publishing Co. 1978.

Although designed primarily for teachers there is a very useful and clear introduction to the family dynamics involving the exceptional child in the family.

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DD RIGHTS CENTER PUBLICATIONS

DD Rights Center

The DD Rights Center of the Mental Health Law Project and the Center on Human Policy is a legal and advocacy backup project funded by the federal Bureau of Developmental Disabilities, which provides assistance to protection and advocacy systems in the following states: Alabama, Alaska, Arkansas, Colorado, Florida, Georgia, Idaho, Iowa, Kansas, Kentucky, Louisiana, Mississippi, Missouri, Montana, Nebraska, New Jersey, New Mexico, New York, North Carolina, North Dakota, Oklahoma, Oregon, Puerto Rico, South Carolina, South Dakota, Tennessee, Texas, Utah, the Virgin Islands, Washington, and Wyoming.

The DD Rights Center has produced a series of advocacy and legal materials relating to the rights of persons with developmental disabilities. These materials are available free of charge to protection and advocacy agencies in the above listed states and at reproduction, handling, and postage costs to other individuals and groups (bulk rates are available on request).

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Understanding the Law: An Advocate's Guide to the Law and Developmental Disabilities
by Steven J. Taylor and Douglas Biklen, $3.25.

The purpose of this manual is to provide consumers and advocates with a better understanding of the law and the legal process. Included in the manual are a glossary of legal terms, an explanation of the system of laws, an overview of the stages of litigation, information on how to research the law, a discussion of how to build a case, and methods for action.

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A HEALTH ADVOCATE'S GUIDE TO THE FEDERAL BUDGET PROCESS

by David F. Chavkin and Yvette Hutchinson***

I. INTRODUCTION

In the early days of health advocacy, nearly the only tool available to improve access was litigation. As health advocates became more sophisticated, however, greater reliance was placed on the complementary tools of legislative and administrative advocacy. Such a multifaceted approach is often necessary to achieve goals that cannot be won through litigation and to protect accomplishments that have been won.[1]

Legislative advocacy has traditionally focused on two aspects of the legislative process — the authorization process and the appropriations process. During the authorization process, new and existing programs are considered by the legislature and sometimes enacted into law. During the appropriaions process, these authorized programs are funded up to the levels set in the authorization bills.

Recently, a third step has been added to this process. This third step is the budget process. While its potential is still relatively unexplored, it may become the most important step in the legislative cycle.

Importance of the Budget Process

The budget process has a direct effect on authorization and appropriations bills. An authorization may establish a positive program for the poor. However, if the budget does not permit this program to be adequately funded, the program purpose will not be realized. Even if an appropriations committee wants to fund a program in an adequate manner, budget limitations may prevent this from happening. Moreover, a budget limitation may force an authorizing committee to actually cut back on an existing program in order to meet budget requirements.

The expanded use by Congress of the reconciliation process[2] poses even a greater threat to programs serving the poor. Through reconciliation, Congress can bypass the normal legislative process to dismantle important social programs. Low-income advocates are often denied an opportunity under reconciliation to even testify on these programs and document their value.

Legislative advocacy on the budget therefore represents an important adjunct of legislative advocacy in other areas. As discussed in this article there are many opportunities for health advocates to influence this process. Just as advocates would no longer limit themselves to litigation in representing the interests of low-income patients, so budget advocacy should not be neglected in engaging in legislative advocacy generally.

II. HISTORICAL EVOLUTION OF THE BUDGET PROCESS

The United States Constitution

The basis of congressional authority over federal expenditures is Article I, Section 8 of the United States Constitution. This section provides that:

> The Congress shall have Power . . . to pay the Debts and provide for the common Defence and general Welfare of the United States [and] . . . To make all Laws which shall be necessary and proper for carrying into Execution the foregoing Powers and all other Powers, vested by this Constitution in the Government of the United States, or in any Department or Officer thereof.[3]

The Constitution further provides:

> No Money shall be drawn from the Treasury, but in Consequence of Appropriations made by Law . . .[4]

Since only Congress can make laws, only Congress can authorize the withdrawal of money from the Treasury. Consequently, these clauses have been construed as a limitation upon the power of the executive branch.[5]

Until 1921

As the United States grew in size and the federal budget grew in complexity, Congress became less and less able to keep pace. Initially, revenue and spending bills were referred to the same committees in each house. In this way, the committees

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[1] The current regulations of the Legal Services Corporation permit legal services workers to engage in legislative advocacy "in response to a request from a . . . legislative body, committee, or member . . [or if] an eligible client . . . may be affected by a particular legislative . . . measure . . . ." 45 C.F.R. §1612.4(a)(1)-(2) (1979).

[2] *See* text accompanying notes 85 and 86 *infra*.

[3] U.S. CONST. art. I, § 8.

[4] U.S. CONST. art. I, § 9.

[5] Cincinnati Soap Co. v. United States, 301 U.S. 308, 321 (1937); Knote v. United States, 95 U.S. 149, 154 (1877).

could balance revenues and expenditures in considering proposed legislation.

In 1865, responsibility for determining spending levels for all activities in the House was transferred to a new "appropriations" committee.[6] Consideration of spending bills was the sole responsibility of this committee. Two years later, a similar committee was established in the Senate.[7] This division of responsibility over revenues and expenditures had the effect of precluding a balancing of outgoing funds with incoming revenues.

Between 1880 and 1920, power struggles within Congress further fragmented budget procedures. While the Appropriations Committees retained jurisdiction over deficiencies[8] and minor bills, powerful legislative committees took over control of the major spending bills. More than half a dozen of the legislative committees in each house had some power over spending policy.[9] In the absence of a central committee within Congress, any coordination of federal budget activities was impossible.

This lack of coordination was not limited to the legislative branch. Prior to 1921, there was no structured executive budget process. Executive agencies lobbied Congress directly. In fact, the lack of budget expertise in Congress often led to noncritical acceptance of the agency recommendations.

Often these agencies took further advantage of the unstructured budget process in Congress. By spending their allocations long before the fiscal year ended, these agencies would be "forced" to seek supplemental funds from Congress in order to operate for the balance of the fiscal year. Congress would then have little choice but to accede.

The Anti-Deficiency Acts of 1905 and 1906 were enacted to curtail this abuse.[10] These acts required agencies to apportion their monies throughout the fiscal year based on estimated expenses. This, it was theorized, would minimize the likelihood that an agency would find its funds depleted before its allocation for the following fiscal year was appropriated. Equally important, Congress viewed the legislation as a means of reasserting control over the budget process.

Budget and Accounting Act of 1921

In 1921, Congress, instead of continuing its efforts to reassert congressional control over the budget, took a different approach. In the Budget and Accounting Act[11] Congress established an executive budget system. Under this system, the President was charged with the responsibility for preparing and submitting to Congress an annual budget.[12] This budget would set forth recommended spending levels. However, Congress would still have to enact these levels into law. To assist the President, Congress also established an executive budget office.[13]

Congress also took some limited steps to strengthen its own budget system. The General Accounting Office was created to audit the government's accounts.[14] This office was also responsible for preparing investigative or analytical reports at the request of Congress.[15] Congress also returned jurisdiction over spending bills to the Appropriations Committees.[16] There was still no central committee to assure overall coordination, however.

Legislative Reorganization Act of 1946

The hope that the Budget and Accounting Act changes would allow Congress to control the budget effectively proved to be short-lived. The Roosevelt administration had taken an expansive view of the role of the federal government and the size of the federal budget had correspondingly increased. In addition, the executive budget system had not filled the need of Congress for technical support and coordinated direction.

The congressional response to these shortcomings was the Legislative Reorganization Act of 1946.[17] Viewed as a major piece of legislation,[18] the act established a Joint Committee on the Legislative Budget made up of the House Appropriations and Ways and Means Committees and the Senate Appropriations and Finance Committees.[19] This Joint Committee was given responsibility for devising a legislative budget to be reported to both houses by February 15 of each year.[20]

Whereas the executive budget represented a summation of agency budget requests, the legislative budget was designed to report two recommended figures — the estimated expenditures and the estimated federal receipts.[21] The Joint Committee was also supposed to recommend a maximum appropriation for the following fiscal year and a reserve for deficiencies, if necessary.[22]

Proponents of the reorganization effort emphasized the need for a balanced budget and reductions in public debt and taxes.[23] The Reorganization Act addressed this concern by requiring Congress to pass a concurrent resolution adopting the budget and fixing a budget ceiling.[24] The act also directed the Joint Economic Committee to recommend a reduction in the public debt should the estimated receipts exceed the estimated expenditures.[25]

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[6] *See* Schick, *Budget Reform Legislation: Reorganizing Congressional Centers of Fiscal Power*, 11 HARV. J. LEGIS 303, 306 (1974).

[7] *Id.*

[8] The term "deficiencies" refers to funds which must be appropriated to agencies to replenish funds depleted prior to the end of the fiscal year for which they were appropriated.

[9] *See* Schick, *supra* note 6, at 306, n.11.

[10] Act of Mar. 3, 1905, ch. 1484, § 4, 33 Stat. 1258; Act of Feb. 27, 1906, ch. 510, § 3, 34 Stat. 27.

[11] Budget and Accounting Act of 1921, § 206, ch. 18, tit. I, 42 Stat. 20 (Codified in scattered sections of 31 U.S.C.).

[12] Budget and Accounting Act, 31 U.S.C. § 11 (1976 & Supp III 1979).

[13] Budget and Accounting Act, 31 U.S.C. § 16 (1976 & Supp. III 1979).

[14] 31 U.S.C. §§ 41, 53 (1976).

[15] *Id.* at § 53

[16] Rules of the House of Representatives, Rule XI, cl. 2 (1973) (originally adopted June 1, 1920); Standing Rules of the Senate, Rule XXV, ¶ 1(c) (1973) (originally adopted Mar. 6, 1922).

[17] Act of Aug. 2, 1946, ch. 753, 60 Stat. 812 (codified in scattered sections of 2, 15, 31, 33, 40 U.S.C.).

[18] *See* Sims, *Federal Legislation: The Role of Congress in Shaping Fiscal Policy — The Legislative Budget*, 36 GEO. L.J. 34, 36 (1947).

[19] Legislative Reorganization Act of 1946, ch. 753, tit. I, § 138(a), 60 Stat. 832.

[20] *Id.*

[21] *Id.*

[22] *Id.*

[23] *See* Sims, *supra* note 18, at 35–36.

Again, the confidence that Congress could assume its budget responsibilities was quickly dissipated. In 1947, the first year that the legislative budget was implemented, Congress failed to pass a budget ceiling.[26] Instead, the appropriations bills were passed without the concurrent resolution required by the statute.[27]

Several factors combined to frustrate the purpose of the act. The Joint Economic Committee was not formed until well into the congressional session.[28] As a result, only limited hearings could be held on the recommended budget ceilings.[29] In addition, there was a lack of clarity about the detail that was supposed to accompany the budget ceiling recommendation.[30] The Joint Economic Committee report only described overall objectives. Some members of Congress wanted a specific breakdown of the areas where cuts would be made before they would approve a budget ceiling that was $6 billion less than that proposed by the President. Finally, in view of the unstable international situation, many members of Congress were unwilling to vote for a ceiling that might require a reduction in military appropriations.[31]

The following year Congress was successful in adopting a spending ceiling for fiscal year 1948.[32] However, Congress ignored this ceiling in approving expenditures.[33] After these first two ineffective years, the system was abandoned.[34]

The Omnibus Appropriations Act of 1950

Congress's inability to achieve coordinated compliance with a budget ceiling extended to its consideration of various appropriations bills. Eleven general appropriations bills and a small number of deficiency and supplemental appropriations bills were enacted each congressional session.[35] Those considered earlier in the year tended to slide through Congress with little opposition.[36] Those bills considered later in the session, however, were often subjected to strict scrutiny.[37] As a result, later appropriations bills were often reduced based not on a comparison of relative worth, but rather based on delayed fiscal caution.[38]

The legislative solution to this problem was the Omnibus Appropriations Act.[39] This act required all appropriations bills to be consolidated in a single omnibus bill.[40] This was supposed to have the effect of giving the appropriations committees an opportunity to review all appropriations measures simultaneously and thereby set a spending ceiling.[41] In the event that the committees did not exercise fiscal restraint, the entire Congress could cut funding either proportionately or based on some determination of relative need or importance.

Like many of the early budget efforts, this proposal lasted only one year. It did result in the timely approval of all the appropriations bills in that year.[42] However, the omnibus appropriations approach was criticized because of fear that a delay in budget authority would result if the President should veto the omnibus bill because of dissatisfaction with one aspect of it.[43] Many legislators disliked it because of the short time available to review the various spending decisions.[44] In addition, many chairmen of the various appropriations subcommittees felt that their powers were reduced by this joint effort.[45] Faced with this widespread dissatisfaction, the Omnibus Appropriations Act was abandoned.

III. THE CONGRESSIONAL BUDGET AND IMPOUNDMENT CONTROL ACT OF 1974

For the next 25 years, Congress took no additional steps to coordinate its fragmented budget activities. Emerging cracks in the budget process, however, highlighted the haphazard method by which Congress was executing its budgetary responsibilities. These problems also highlighted the urgent need for further legislative reform.

Continuing Resolutions

In theory, appropriations bills are passed by Congress and signed by the President before the beginning of each fiscal year. During the early 1970's, however, approximately half of the appropriations bills were still pending on each July 1, the beginning of the fiscal year. Congress was therefore forced to pass continuing resolutions.

Under a continuing resolution, temporary funding is provided for federal agencies for a limited period. Continuing resolutions therefore serve an important purpose by preventing the shutdown of one or more agencies. They are not without drawbacks, however.

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[24] Legislative Reorganization Act of 1946, ch. 753, tit. I, § 138(b), 60 Stat. 833, *repealed by* Act of Oct. 26, 1970, Pub. L. No. 91-510, tit. II, part 4, § 242(b)(1), 84 Stat. 1172.

[25] *Id.* at § 138(a).

[26] *See* Sims, *supra* note 18, at 44.

[27] *Id.*

[28] *Id.* at 45.

[29] *Id.* at 44.

[30] 93 CONG. REC. 1419 (1947) (remarks of Senator McMahon); *Id.* at 1430 (remarks of Senator Morse).

[31] *See* 93 CONG. REC. 1336 (1947) (remarks of Senator Cain); *Id.* at 1421 (remarks of Senator Barkley); *Id.* at 1422 (remarks of Senator Byrd).

[32] H.R. REP. NO. 658, 93d Cong., 1st Sess. 27, *reprinted in* [1974] U.S. CODE CONG. & AD. NEWS 3462, 3473.

[33] *Id.*

[34] *Id.* The budget ceiling provision was eventually rescinded by the Legislative Reorganization Act of 1970. This act improved the availability of budget information to Congress, but did not address the budget process. *See* Abascal and Kramer, *Presidential Impoundment Part II: Judicial and Legislative Responses*, 63 GEO. L.J. 149, 171 (1974).

[35] *See* Sims, *supra* note 18, at 43.

[36] *Id.*

[37] *Id.*

[38] *Id.*

[39] General Appropriations Act for Fiscal Year 1951, Act of Sept. 6, 1950, ch. 896, 64 Stat. 595.

[41] *Id.*

[42] *See* Schick, *supra* note 6, at 307.

[43] H.R. REP. NO. 658, 93d Cong., 1st Sess. 28, *reprinted in* [1974] U.S. CODE CONG. & AD. NEWS 3462, 3474.

[44] *Id.*

[45] *See* Schick, *supra* note 6, at 307-308.

Continuing resolutions set temporary spending levels for the interim period. There is no certainty that this level will be maintained or increased in the final appropriations for the agency. As a result, it is difficult to plan effectively the operations of the agency for the full fiscal year. Similarly, continuing resolutions invite the kind of agency abuse addressed by the Anti-Deficiency Acts of 1905 and 1906. Faced with a time-limited appropriation, an agency may spend its temporary funding quickly. In this way, Congress can be forced to appropriate more than it had originally intended.

Uncontrollable Expenditures

By the 1970's, approximately three fourths of the federal budget was characterized as "uncontrollable" under existing law.[46] These expenditures are "uncontrollable" in the sense that it is extremely difficult for Congress to make adjustments in a current program's level of funding. The "uncontrollable" nature of these programs is due to the use of backdoor spending authority.

Backdoor spending includes any budget authority which is not provided through appropriations considered by the appropriations committees of the two houses. The normal chain of events for spending measures is authorizing legislation, appropriations, and then the obligation of funds by the recipient agency. In backdoor spending, the authority to obligate funds is granted first. Congress' role under these circumstances is ministerial in nature.

Four types of backdoor spending are commonly used. These four types are entitlements, contract authority, borrowing authority, and permanent appropriations. For health advocates, probably the most important of these is entitlements.

Entitlements

Health entitlements include the Medicare and Medicaid programs. Under these programs the outlays are defined by the scope of the authorizing legislation. Those persons who meet the eligibility requirements of the programs are legally entitled to receive specified benefits. Thus, Congress is bound to fund these programs at the level necessary to fulfill the obligations owed to program beneficiaries.

Outlays under the entitlement programs must necessarily be estimated by Congress. Outside forces determine the exact amounts that Congress will be forced to provide. Health status of Medicaid recipients, for example, will in part define the costs of the program. Inflation in the health care sector will also affect the outlays for medical care. Similarly, increased unemployment in the nation may increase the numbers of families seeking public assistance benefits, including Medicaid.

In contrast to the entitlements are the discretionary spending programs. The funding levels for the discretionary programs must be set annually in the appropriations process. If less money is appropriated, the programs must also necessarily be circumscribed. The discretionary health programs include family planning, community health centers, and health prevention.

Since discretionary programs can be gutted during the appropriations process, there is a strong incentive for legislators sponsoring new programs to draft these bills as entitlements. In this way, the integrity of the legislation can be largely insulated from subsequent congressional review. In fact, the recent past has seen a substantial increase in the percentage of the federal budget attributable to entitlement programs.[47]

Contract Authority

Agencies use contract authority to enter into obligations in advance of appropriations. Appropriations are then made to liquidate the contract obligations. The appropriations committees therefore have no real control over this type of spending. They must recommend amounts necessary to meet these outlays.

The use of contract authority is also extremely popular. From 1967 to 1972, the amount of contract authority included in the federal budget always exceeded $8 billion.[48] The figure for Fiscal Year 1973 was close to $20 billion.

Contract authority can be useful in allowing lead time for long-term projects. However, the use of contract authority limits the ability of Congress to regulate current outlays. If Congress adds new contract authority, the total cost may not be reflected in current fiscal year outlays but in future outlays. Conversely, a reduction in appropriations will have little effect on current outlays based on previously exercised contract authority.

Borrowing Authority

Borrowing authority involves the authority to obligate and spend from funds obtained by borrowing from the Treasury or the public. Unlike normal appropriations, borrowing authority is both indefinite in amount and duration.

Borrowing authority is used to fund such programs as health professions loan guarantees. Funds are borrowed from the Treasury and the public in indefinite amounts. This authority remains available for reborrowing once a loan has been repaid. There is no appropriations limitation on it.

As with other types of backdoor spending, the appropriations committees have little control over these expenditures. From 1932 to 1972, Congress authorized $130 billion in borrowing authority.[49] Of that amount, only $15 billion had been reviewed through the appropriations process. The remaining $115 billion had been handled solely by legislative committees.

Permanent Appropriations

The fourth type of backdoor spending is a permanent appropriation. Under a permanent appropriation, funds are made available for a designated period of time. No further congressional action is necessary to authorize annual spending.

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[46] The Budget of the United States Government, Fiscal Year 1974, at 333 (1973).

[47] H.R. Rep. No. 227, 96th Cong., 1st Sess. 5 (1979).

[48] Subcommittee on Budgeting, Management and Expenditures of the Senate Committee on Governmental Operations, 93rd Cong., 1st Sess., Improving Congressional Control over the Budget: A Compendium of Materials 301 (A. Schick, Backdoor Spending Authority) (Comm. Print 1973).

[49] *Id.* at 294.

Social security benefits are an example of permanent appropriation. These appropriations are indefinite as to amount and duration. In contrast, revenue sharing is a permanent appropriation which is specific in both amount and duration.

The number of permanent appropriations rose at a much faster rate than federal spending as a whole before 1974.[50] By Fiscal Year 1974, nearly one quarter of the federal budget was in the form of permanent appropriations.[51] Again, the appropriations committees had no opportunity to review these appropriations on an annual basis and thereby coordinate such spending with the broader federal budget.

Impoundment

Problems with enacting appropriations bills and coordinating the federal budget were not the only problems facing Congress in the early 1970's. At the same time that Congress was acknowledging its lack of control over total federal expenditures, it was also involved in a power struggle with the President to assure that appropriated funds were actually spent by the executive branch.

In Fiscal Year 1973, President Nixon decided to keep federal outlays below $250 billion. This determination was expressed in several different ways. Two Labor/HEW Appropriations bills were vetoed by the President because they exceeded Administration budget estimates. As a result, Congress was forced to adopt a continuing resolution to keep these two agencies in operation.

This initial skirmish set the tone for the impoundment struggles to come. In February 1974, the Administration admitted to having impounded or delayed $11.8 billion in appropriated funds.[52] In addition, another $6 billion had been impounded in violation of the Federal Water Pollution Control Act Amendments of 1972.[53] All of these impoundment actions were justified by the Administration as being necessary to control federal spending and its effect on inflation.[54]

President Nixon was not the first president to impound funds. As long ago as the Jefferson administration, presidents had refused to spend monies appropriated by Congress. The amounts impounded by the Nixon administration far exceeded earlier efforts, however.

President Nixon attempted to base his authority to impound funds on the 1950 amendments to the Anti-Deficiency Acts of 1905 and 1906.[55] This legislation granted the Office of Management and Budget the discretion to establish budget reserves "to provide for contingencies, or to effect savings whenever savings are made possible by or through changes in requirements or greater efficiency of operations."[56]

The President's choices of programs to target for impoundment did not reflect efforts to effect savings or to promote efficiency of operations. Instead, they represented those programs that were not given a high priority in his budget message. In effect then, impoundment was being used to override congressional decisions on the importance and level of funding necessary for certain programs.

These impoundment efforts did not go unnoticed nor unchallenged. Over 30 law suits were filed against the Administration, generally by those persons who lost funding as a result of the President's actions. Several of these cases were brought to require the President to release $1 billion of the $1.8 billion in HEW funds impounded in Fiscal Year 1973.

In all of these cases, the congressional power under the Constitution to authorize programs and appropriate funds was undisputed. The inquiry did not end there, however. The determining factor, in the courts' decisions, was whether the impoundment was contrary to an expressed intent on the part of Congress that the programs operate on a full-scale.

In evaluating intent, the courts considered the presence of mandatory spending language or inferences of directives in the measures' legislative history. Thus, for example, in *National Council of Community Mental Health Centers, Inc. v. Weinberger,* the court ordered the expenditure of $52.1 million.[57] In reaching this conclusion the court stated that the President

> does not have complete discretion to pick and choose between programs when some of them are made mandatory by conscious deliberate congressional action.[58]

In other cases the court looked to the purposes of the particular program to determine whether the excepting provisions in the Anti-Deficiency Act applied. The excepting provision precludes the withholding of funds, for whatever reason, when to do so would thwart the policy or effectiveness of the enabling act.[59] Even where mandatory language was not found, or where the language was ambiguous, some courts inferred a directive to spend appropriated funds. This approach viewed a congressional decision to keep a statute on the books as manifesting the requisite intent not to terminate or cripple a program.[60]

The final scorecard indicated that the President lost at least 25 of the approximately 30 cases brought against his impoundment actions.[61] Although Congress was largely victorious, it was dissatisfied with its dependence on the judiciary. As a result, Congress established a Joint Study Committee on Budget Control.[62] This committee was to recommend improvements in "congressional control of budgetary outlay and receipt totals."[63] Again, the wheels had been set into motion for Congress to reimpose control over the federal budget.

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[50] *Id.* at 296.

[51] *Controllability of Budget Outlays*, in THE BUDGET OF THE UNITED STATES GOVERNMENT, FISCAL YEAR 1974 (1973).

[52] 39 Fed. Reg. 7708, 7714 (1974).

[53] Federal Water Pollution Control Act Amendments of 1972, 33 U.S.C. § 1251 (1976). *See also* 29 CONG. Q. ALMANAC 254 (1973); 39 Fed. Reg. 7708 (1974).

[54] State Highway Comm'n of Mo. v. Volpe, 479 F.2d 1099, 1103 (8th Cir. 1973).

[55] *See, e.g.*, Impoundment of Appropriated Funds by the President, Joint Hearings Before the Senate Committees on Government Operations and the Judiciary, 93d Cong., 1st Sess. 269-272 (1973) (Statement of Roy Ash, Director-designate of the Office of Management and Budget); Act of Sept. 6, 1950, ch. 896, § 1211, 64 Stat. 765, *as amended* 31 U.S.C. § 665(c)(2) (1976).

[56] Act of Sept. 6, 1950, ch 896, § 1211, 64 Stat. 765, *as amended* 31 U.S.C. § 665(c)(2) (1976).

[57] National Council of Community Mental Health Centers v. Weinberger, 361 F. Supp. 897 (D.D.C. 1973).

[58] *Id.* at 902.

[59] H.R. REP. No. 1797, 81st Cong., 2d Sess. 311 (1950).

[60] State Highway Comm'n of Mo. v. Volpe, 479 F.2d 1099, 1115-16 (8th Cir. 1973). *See generally* National Council of Community Mental Health Centers v. Weinberger, 361 F. Supp. 897 (D.D.C. 1973).

IV. THE BUDGET TIMETABLE

The Congressional Budget and Impoundment Control Act of 1974 established a new fiscal year for the federal government[64] and a new timetable[65] for budget actions. That calendar also defines the role that health advocates can play in influencing that budget.

> **October 1** — The federal fiscal year begins.[66] The Congressional Budget Office issues its report on five-year projections of spending, revenues, and tax expenditures.[67]
>
> **November 10** — The President submits a current services budget to Congress.[68]
>
> **December 31** — The Joint Economic Committee submits its economic review of the President's current services budget to the Committees on the Budget.[69]
>
> **January (middle)** — The President submits his budget for the next fiscal year 15 days after Congress convenes.[70]
>
> **March 15** — All committees and joint committees submit to Budget Committees reports providing advice and data.[71]
>
> **April 1** — The Congressional Budget Office submits reports to Budget Committees.[72]
>
> **April 10** — President submits changes in his January budget.[73]

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[61] *Impoundment: Administration Loses Most Court Tests*, 29 CONG. Q. ALMANAC 253 (1973).

[62] Act of Oct. 27, 1972, Pub. L. No. 92-599, § 301, 31 U.S.C. §757B note (1976).

[63] *Id.*

[64] Cong. Budget and Impoundment Control Act of 1974, § 501, 31 U.S.C. § 1020 (1976).

[65] 31 U.S.C. § 1321 (1976).

[66] The fiscal year was primarily revised to give Congress three additional months in which to consider policy issues while deliberating over program spending levels. A second reason for the change was to reduce the likelihood of continuing resolutions to continue funding for programs which had not been acted upon before the start of the fiscal year.

[67] The Congressional Budget Office was established by Title II of the act. The Office, a nonpartisan organization, functions as an arm of both houses of Congress by providing budget-related information and objective analyses of alternative fiscal, budgetary and programmatic policies. Its responsibilities do not include recommendations on matters of policy. Its specific tasks include five-year budgetary cost estimates of proposed legislation, tracking of congressional budgetary actions against budget targets established by the Concurrent Resolution (known as scorekeeping), periodic forecasts of economic trends and alternative fiscal policies, and analyses of budgetary issues as they affect social needs. 2 U.S.C. § 602. The Congressional Budget Act specifically provides that:

> As soon as practicable after the beginning of each fiscal year, the Director of the Office shall issue a report projecting for a period of 5 fiscal years beginning with such fiscal year –
> (1) total new budget authority and total budget outlays for each fiscal year in such period;
> (2) revenues to be received and the major sources thereof, and the surplus or deficit, if any, for each fiscal year in such period; and
> (3) tax expenditures for each fiscal year in such period. 31 U.S.C. § 1329 (1976).

[68] The current services budget describes anticipated budget authority and outlays which would be included in a budget for the upcoming fiscal year based on the present fiscal year budget without policy changes. The estimates are based on the projected budgetary impact of such factors as unemployment and inflation. The estimates are shown by function and subfunctions within each major agency. 31 U.S.C. § 11 (1976 & Supp. III 1979).

[69] The Joint Economic Committee received its mandate from the Employment Act of 1946, 15 U.S.C. § 1024 (1976 & Supp. III 1979). Its focus is on economic policy issues. The Committee, which is partisan, considers long range economic implications for legislative and budget committees. 31 U.S.C. §11a (1976).

[70] This budget must include levels of tax expenditures under existing laws for the present fiscal year. It must also contain a comparison of the estimated total outlays for each program having backdoor status and the total amount of outlays made under each program during the last completed fiscal year. Also, the total estimated revenues in the President's budget must be compared to the total revenues received during the last completed fiscal year. Furthermore, with respect to each major revenue source, the President must compare the amount of revenues estimated in his Budget and the amount received during the last completed year. The law also requires an analysis and explanation of any differences in the comparisons made. 31 U.S.C. § 11(a) (1976 & Supp. III 1979).

[71] Each standing committee in the House is required to submit to the House Committee on the Budget, each standing committee in the Senate must submit to the Senate Committee on the Budget, and the Joint Economic Committee and the Joint Committee on Taxation must submit to both Budget Committees, their views and estimates with respect to matters within their jurisdiction as they relate to the budget. 31 U.S.C. § 1322(c)-(d) (1976 & Supp. III 1979). The Joint Economic Committee, for example, would submit what it believes to be the appropriate level of total budgetary outlays and of total new budget authority. A legislative committee, like the Subcommittee on Health and the Environment of the House Energy and Commerce Committee, would provide an estimate of budget outlays and an appropriate level of new budget authority for programs within its jurisdiction. The Joint Economic Committee must also submit a report of the amount of any surplus or deficit in the budget that is appropriate in light of economic conditions and other relevant factors. The Senate Finance Committee and House Ways and Means Committee would each submit a recommended level of federal revenues and any amount by which the total level of federal revenues would be increased or decreased by bills and resolutions to be reported by the committees. A level for the public debt would most likely be recommended by the Joint Economic Committee, Senate Finance Committee and House Ways and Means Committee.

[72] This should encompass levels of total revenues, total new budget authority, and total outlays (including related surpluses of deficits). Also included are tax expenditure levels under existing law, taking into account projected economic factors and any possible changes in such levels due to proposals in the President's budget. This report should include a discussion of national budget priorities. 2 U.S.C. § 602(1) (1976).

[73] The President may find it necessary or appropriate, based on recent information, to amend or revise the budget authority request, estimated outlays, or estimated receipts. These changes may be submitted on April 10 or on July 15. If the President does submit revisions, a statement must be included describing the effect of the revisions on the summary data to the original budget proposal. 31 U.S.C. §11(g) (1976).

April 15 — The House and Senate Budget Committees report the First Concurrent Budget Resolution to their houses.[74]

May 15 — House and Senate Committees report bills and resolutions authorizing new budget authority.[75]

May 15 — Congress completes action on the First Concurrent Budget Resolution.[76]

July 15 — The President transmits his Mid Session Review of the Budget.[77]

7 days after Labor Day — Congress completes action on bills and resolutions providing new budget authority and new spending authority.[78]

September 15 — Congress completes action on the Second Concurrent Resolution on the budget.[79]

September 25 — Congress completes action on reconciliation bill and/or resolution implementing the Second Concurrent Resolution.[80]

The Major Stages

The Administration Budget

Probably the most important stage at which to influence the federal budget is before the budget is presented to Congress in January. If your recommendations have already been included in the Administration budget, it will be much easier to persuade members of the Budget Committees and Appropriations Committees to accept your recommended level of funding. This is because the impact has already been considered and the budget estimates already include attributable costs. As always, it is easier to defend something that is already in the budget than to add something that was not included initially.

The Administration budget is prepared during the summer and fall of the preceding fiscal year. Thus, the Fiscal Year 1982 budget (which begins October 1, 1981) was developed within the Administration during the summer and fall of

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74. This resolution establishes targets for budget authority, outlays, revenues, deficit or surplus, and public debt. It is a product of all the reports received from the various congressional committees. The report accompanying the resolution must include a comparison of the Committee's estimates and those in the President's budget proposal. 31 U.S.C. §1322(d) (1976 & Supp. III 1979).
75. No bills or resolutions which would directly or indirectly authorize the enactment of new budget authority for a fiscal year can be considered by either house unless the legislation is reported on or before May 15 prior to the beginning of the fiscal year. The cut-off date allows the appropriations committees to work on distributing their allocated level of new budget authority for proposed new programs without the periodic interruption of authorizing legislation. Without a cut-off date, the appropriations bills would be subject to continuous revisions by each committee to reflect requests for new spending.

    An exception to the deadline is possible where the Committee on Rules in the House determines that an emergency waiver is warranted. In this instance, the Committee would report a resolution waiving the restriction for the particular legislation for House consideration. In the Senate, the authorizing or appropriations committee can report its bill, but must also report to the Senate a resolution for waiver of the limitation explaining the need for the waiver. The resolution must then be referred to the Senate Budget Committee and finally reported to the Senate for consideration.

    If the resolution in either the House or Senate is agreed to, the legislation authorizing the budget authority can be brought to the floor for consideration. Furthermore, if a committee in the House has reported a measure within the May 15 deadline, the House can consider the companion legislation already passed by the Senate. The reverse also holds true. This procedure is provided to conform to the normal procedure that the House or Senate must consider the exact bill passed by the other house that completed action first. 31 U.S.C. § 1352 (1976). *See generally* S. Conf. Rep. No. 924, 93rd Cong., 2d Sess. 66, *reprinted in* [1974] U.S. Code Cong. & Ad. News 3591, 3608.
76. Congress has until May 15 to adopt the First Concurrent Budget Resolution. This deadline gives Congress ample time to become adequately informed of the contents of all authorizing legislation so that it can make its initial budget determinations. This resolution must be adopted before legislation providing new budget authority, new spending authority, or changes in revenues or the public debt limit can be considered. 31 U.S.C. §1322(a)-(b) (1976 & Supp. III 1979).
77. This provision amended the Budget and Accounting Act of 1921. It provides that the President has until July 15 to submit a second statement on any amendments or revisions in the figures put forth in his original budget message or in the statement transmitted in time for the April 10 deadline. Congress required these updates so that its final consideration of the budget would be based on the most recent information available. 31 U.S.C. §11(b)-(c) (1976).
78. This deadline is an important one since Congress has only three weeks remaining, after this date, until the beginning of

78. *(cont'd)*
    the new fiscal year. During these three weeks the Second Concurrent Budget Resolution and any necessary reconciliation bills must be adopted. This time legislation does not apply to supplemental, deficiency, or continuing appropriations bills and resolutions. Also expected are any spending or entitlement bills which are delayed because of a failure to timely enact legislation authorizing the enactment of new budget authority to be provided in the spending or entitlement measure. *See* note 75 *supra*. *See also* S. Conf. Rep. No. 924, 93rd Cong., 2d Sess. 62, *reprinted in* [1974] U.S. Code Cong. & Ad. News 3591, 3604.
79. The Second Concurrent Resolution on the Budget is reported by each Budget Committee. This resolution must affirm or revise the First Budget Resolution. It must specify the amount of spending and budget authority, revenue and public debt legislation, and must direct the appropriate committees to determine and recommend necessary changes. 31 U.S.C. §1331(a)-(b) (1976).
80. The act describes a reconciliation resolution or bill as a concurrent resolution directing the clerk of the House of Representatives or the secretary of the Senate, as the case may be, to make specified changes in bills and resolutions which have not been enrolled. 31 U.S.C. §1331(c) (1976). If the changes requested in the Second Concurrent Resolution only need to be made by one committee in each house, that committee will follow the Resolution's directions. It will then report to its house a reconciliation bill or resolution, or both, which should contain such recommendations. Where more than one committee in each house has received directions to recommend changes, all such committees must submit their recommendations to the Committee on the Budget in their respective houses. Each Budget Committee then reports to its house a reconciliation resolution comprised of the recommendations made by all the committees and submitted without substantial revision by the Budget Committees. Sometimes a reconciliation bill may need to be considered for changing matters already enacted into law. An example is changing entitlement authority which can only be reduced through changes in the authorizing legislation. 31 U.S.C. §1331(c)-(d) (1976); *see* S. Conf. Rep. No. 924, 93d Cong., 2d Sess. 63, *reprinted in* [1974] U.S. Code Cong. & Ad. News 3462, 3605.

1980. Although the Administration also uses three-year budget projections, the changing political considerations and fiscal realities provide ample opportunity to influence the budget process during this period.

The health budget is initially developed by the Department of Health and Human Services.[81] Each of the principal operating components(POCs)[82] within the Department prepares its own budget projections of existing programs, its requests for new programs, and its proposals for phasing out existing programs.[83] After being approved within the principal operating component, often after substantial modifications, the proposed budget is transmitted to the Assistant Secretary for Management and Budget (ASMB).

The Assistant Secretary for Management and Budget performs many of the functions within the Department that the Director of the Office of Management and Budget performs for the President. All budget estimates are reviewed. All programs are scrutinized for cost-effectiveness and new programs especially must be justified. Often the Assistant Secretary's office will disapprove the submitted budget in one or more areas.

In the event of disapproval, the principal operating component representative has two options. Either the budget can be revised to conform to the ASMB position or the questioned expenditure(s) can be appealed to ASMB and ultimately to the Secretary. The Secretary can then sustain the ASMB position, agree with the POC representative, or approve a compromise position. In practice, often all three alternatives take place with regard to different aspects of the budget.

After the Secretary approves the budget for the Department, it is transmitted to the Director of the Office of Management and Budget. The process that took place within the Department is then repeated within OMB. Programs and expenditures are reviewed and exceptions are taken to specific aspects of the proposed budget. Negotiations often take place between ASMB and OMB representatives. Disagreements can be appealed by the dissatisfied agency to OMB. Differences that cannot be resolved through negotiations or OMB appeal are sometimes appealed to the White House. Finally, a proposed budget is approved for submission by the President to Congress as part of the overall federal budget.

There are ample opportunities for health advocates to influence this process. During the initial stage, advocates can contact program staff to urge expansions of specific programs or requests for new programs. Advocates can also contact the directors of the various POCs to advocate, from the top down, that certain budget changes be made. If it is learned that certain desired programs have been disapproved by the HHS ASMB, health advocates can attempt to buttress the presentations by the POC representative by demonstrating the widespread public support for and wisdom of the questioned expenditure. These steps can also be repeated at the OMB and, White House levels.

The Budget Hearings

After the President's budget is received, it is referred in both houses of Congress to the Budget Committees. The two budget committees establish targets for appropriations and other forms of spending for each of 19 functional areas in the budget. Health is one of these areas and is assigned budget function category 550.

Hearings are held on the President's budget during the first few months of the congressional session. Initial witnesses usually come from the White House and are followed by witnesses from each of the Departments and other executive agencies. Occasionally, congressional and public witnesses are also invited to testify.

First Concurrent Resolution

After the hearings, the budget committees begin to "mark-up" the First Concurrent Budget Resolution. The committees generally start with the President's proposed budget figures, and decide whether the proposed levels of budget authority and outlays are appropriate. (Budget authority is the legal authority to enter into obligations which will require either immediate or future expenditures of government funds. Outlays are the actual expenditures in any fiscal year pursuant to such budget authority, offset by any refunds or reimbursements.) Certain programs supported by key legislators or interest groups may receive increased funding over the levels recommended in the President's budget. Other programs may be reduced or eliminated completely.

In addition to reviewing proposed budget authority and outlays, the committees review the proposed figures for revenues. With the assistance of the Congressional Budget Office, the committees decide if the revenue levels estimated by the President seem correct. If not, different revenue levels based on estimated receipts from the present tax system may be substituted.

After comparing the proposed outlays and revenues, a tentative surplus or deficit is established. If the proposed budget would result in a deficit, the budget committees may decide either that outlays should be decreased or that revenues should be increased in order to balance the budget or reduce the deficit. Specific recommendations might then be included in a concurrent budget resolution that would direct the applicable committees with jurisdiction to make these changes. These committees would then have the responsibility to report legislation accomplishing these results. This process is known as reconciliation.

After each budget committee develops a proposed budget, the budget resolutions are reported to the full House and Senate. Each house then considers the budget resolution along with any floor amendments. A budget resolution is then passed and sent to the other chamber for consideration. Since the Constitution requires that spending bills originate in the House,[84] Senate action generally follows House consideration. The first budget resolution is therefore generally referred to by its House Joint Resolution number.

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[81] The Department of Health, Education and Welfare was divided into two departments by the Department of Education Organization Act 20 U.S.C. §3508 (Supp. III 1979). The Department with continuing responsibility for health programs is the Department of Health and Human Services.

[82] Principal operating component (POC) refers to a major organizational entity within the Department of Health and Human Services. POCs include the Public Health Service, the Health Care Financing Administration, and Social Security Administration.

[83] Within each principal operating component, the particular branch or office does much of the initial work in developing its budget and advocating adoption of those figures. Thus, for example, within the Office of the Secretary of Health and Human Services, the Office for Civil Rights develops its own budget and must first persuade the Office of the Secretary to accept those figures.

After both the House and Senate have passed their versions of the first budget resolution, a conference is held to resolve any differences in the two versions. Generally the conference committee consists of members of the House and Senate budget committees. After a conference committee version is developed, the full House and Senate must approve the changes before final passage.

Again, there are many opportunities for health advocates to influence the shape of the budget resolution. Advocates can request an opportunity to testify at the budget hearings. Members of the budget committees can be contacted and urged to support programs important to low-income persons. At the time of full House or Senate deliberations, health advocates can work with sympathetic legislators in developing needed amendments and in seeking expenditures that are more responsive to the needs of low-income clients.

While economists, actuaries and other highly trained persons participate in the development of the federal budget, health advocates should not be intimidated by these credentials. Often the most needed and most effective advocacy is simply an explanation of how a program affects people in a particular way and therefore why it is needed. For example, low-income clients can describe what it was like in their community before the advent of the National Health Service Corps and what differences a National Health Service Corps doctor has made.

Authorizations and Appropriations

During the period between passage of the First Concurrent Budget Resolution and the beginning of consideration of the Second Concurrent Budget Resolution, Congress considers most substantive legislation and all of the 13 separate appropriations bills. Although authorizing legislation can be considered by Congress at any time, there are usually many measures that just barely meet the reporting deadline of May 15. Thus, they are scheduled for consideration by Congress during the summer months.

Appropriations, on the other hand, cannot be adequately addressed by the Appropriations Committees until they are aware of what authorizing legislation will meet the May 15 reporting deadline. Only then can they determine how many programs and activities will require budget authority and the extent of their need in distributing such authority.

The Second Concurrent Budget Resolution

Because the First Budget Resolution is adopted in May, four and one-half months before the beginning of the fiscal year, many of the assumptions used in the First Resolution may prove incorrect. Unemployment may increase, thereby increasing expenditures for such programs as unemployment compensation and reducing revenues from payroll taxes. Inflation may increase beyond the estimated figures, thereby increasing expenditures for entitlement programs.

For this reason, the First Budget Resolution only sets targets for expenditures, revenues, deficit or surplus, and the public debt. As the beginning of the fiscal year gets closer, the budget committees can refine their predictions. These refined predictions are implemented in the form of a Second Concurrent Budget Resolution.

The Second Resolution sets binding figures for outlays and revenues. The Second Resolution also provides an opportunity to revise the policies underlying the First Budget Resolution. For example, Congress may have been caught up in a "balanced budget fervor" at the time of the First Budget Resolution. Thus, many social programs may have been cut back in order to balance the budget. By September, however, the country may be in a recession. The normal way to attack a recession is to cut taxes, increase spending on social programs, and incur a budget deficit. These revisions can therefore be made in the context of the Second Resolution.

Reconciliation

Congressional action may have increased new budget authority, spending authority, and revenue or public debt limits beyond the final budget resolution totals. The Second Budget Resolution might therefore direct the committees with jurisdiction of those matters to report legislation that would make the excessive levels comport with those in the resolution.[85] This procedure is known as the reconciliation process.

The committees with jurisdiction over the major health programs are the Senate Finance Committee (Medicare and Medicaid), the Senate Labor and Human Resources Committee (Health Planning and Resources Development, Health Personnel), the House Energy and Commerce Committee (Medicaid, Medicare Part B, Health Planning and Resources Development, Health Personnel, PSROs), and the House Ways and Means Committee (Medicare Part A). Under reconciliation, these committees must propose specific measures to bring spending within specific limits.[86] These measures are then included within the House or Senate version of the Reconciliation bill.

Since a reconciliation bill is designed to effect savings, the role of the health advocate is primarily defensive. The goal is to ensure that cuts are made in programs that will not adversely affect low-income clients. Advocates must therefore work with committee staff and legislators to describe the impact of proposed cuts on low-income persons and to recommend alternatives or ameliorating provisions.

Reconciliation directives may be included in either the First or Second Concurrent Resolution or in both. Although the Congressional Budget Act specifically provides for a reconciliation procedure in the Second Concurrent Resolution, the Budget Committees found the use of the reconciliation procedure in the First Concurrent Resolution to be legitimate in their efforts to balance the budgets for Fiscal Years 1981 and 1982.

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[84] U.S. Const. art. I, § 7.

[85] 31 U.S.C. §1331(a) (1976).

[86] 31 U.S.C. §1331(c) (1976).

By the time that the Second Resolution is receiving active consideration in Congress, there is ordinarily little time to really advocate changes. The Second Resolution should be approved by September 15 (although target dates are not always met). Active consideration of the resolution does not usually begin until September.

Therefore, if major changes are needed in the First Budget Resolution, legislative advocacy for these changes should begin several months earlier. Again, the executive branch of government should not be overlooked. Changes in the budget advocated by the President are more likely to be accepted by the budget committees and ultimately by Congress.

Rescission and Deferral

In response to President Nixon's impoundment actions, Congress adopted provisions to curb future efforts to impound appropriated funds. The Congressional Budget and Impoundment Control Act of 1974 addressed this problem by establishing a procedure for congressional reconsideration of appropriations. Two types of impoundment alternatives were established — rescission and deferral.[87]

Three types of rescission actions are recognized in the act.[88] First, the President may determine that all or part of any budget authority is not necessary to carry out the purposes or scope of programs for which it was provided. Second, the President may decide that certain budget authority should be rescinded for fiscal policy or other reasons (including termination of authorized projects or activities). Third, the President may decide to reserve all or part of certain budget authority where that authority was provided for only one fiscal year. This is a rescission because the budget authority cannot be rolled over into subsequent fiscal years. Any conduct or decision fitting into any or all of these definitions constitutes a rescission.

If the President intends to rescind any budget authority, he must submit a special message to Congress requesting congressional approval of his proposal.[89] The message must include the amount of budget authority which he proposes to rescind, the government beneficiary of that budget authority, the reasons for seeking such action, the estimated fiscal, economic and budgetary effects of the implementation of the proposal, and any related facts, circumstances and considerations.

The special message is then considered in the form of a bill. If Congress does not complete action on the rescission bill within 45 calendar days after the President's message was received by Congress,[90] the budget authority targeted by the President must be made available for obligation,[91] that is, the funds proposed to be withheld must be spent.

Deferral of budget authority is defined as the withholding or delaying of obligation or expenditure of budget authority.[92] Deferral also includes any type of executive action or inaction which "effectively precludes" the obligation or expenditure of budget authority.[93]

If any United States government employee seeks to defer budget authority, the President must transmit a special message to Congress.[94] The act requires that the message must specify the amount of budget authority proposed to be deferred, the government agency for which the budget authority is sought to be deferred, the reasons for the deferral, and any legal justification for the proposed action.[95] If either the Senate or the House passes an impoundment resolution disapproving such proposed deferral at any time after receipt of the message, the authority must be made available for obligation.[96]

Health advocates can affect this process by raising their concerns with the members of the committee in each house to which the special message has been referred. A resolution of disapproval may then be reported. The text of any recission or deferral message can be found in the first issue of the *Federal Register* published after transmittal of the message.[97]

Comptroller General[98]

The Comptroller General also plays an important role in the impoundment control process. In addition to the House and Senate, a copy of the President's special message proposing a rescission or deferral must be delivered to the Office of the Comptroller General.[99] The Comptroller General is responsible for informing Congress of the probable effects of the proposed action and, for deferrals, if the proposed deferral is in accordance with existing statutory authority.[100]

If any action or inaction constituting a rescission or deferral has not been reported to Congress, the Comptroller General must make a report on such action or inaction.[101] This report is treated as if it were a special message from the President for purposes of congressional review.[102] Moreover, if the Comptroller General believes that the President has incorrectly classified a deferral or rescission action in a message, the Comptroller General must make a report to both houses of Congress explaining the reasons for such belief.[103]

Again, the health advocate can provide input. The special message can be analyzed to determine whether the President has correctly categorized the proposed action. If a rescission has been categorized as a deferral, the advocate can alert the Comptroller of the fact to ensure that the proper procedure is followed.

Classification of a proposed action is an important step because of the different procedure for rescissions than for deferrals. Funds may not be rescinded in the absence of an affirmative act by Congress (passage of a rescission bill). By contrast a proposed deferral will be effective in the absence of an affirmative act by Congress ordering the funds to be spent.

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[87] 31 U.S.C. §1401 (1976).
[88] 31 U.S.C. §1402(a) (1976).
[89] *Id.*
[90] 31 U.S.C. §1401(5) (1976).
[91] 31 U.S.C. §1402(b) (1976).
[92] 31 U.S.C. §1401(1) (1976).
[93] *Id.*
[94] 31 U.S.C. §1403(a) (1976).
[95] *Id.*
[96] 31 U.S.C. §1403(b) (1976). *See generally* 31 U.S.C. §1407 (1976) (laying out congressional procedures for considering rescission bills or a request for deferral of budget authority).
[97] 31 U.S.C. §1401(a)-(d) (1976).
[98] The Office of the Comptroller General is part of the General Accounting Office (GAO). The GAO is the primary investigatory arm of Congress in meeting its oversight responsibilities.
[99] 31 U.S.C. §1404(b) (1976).
[100] *Id.*
[101] 31 U.S.C. §1405(a) (1976).
[102] *Id.*
[103] 31 U.S.C. §1405(b) (1976).

In the event of a proposed rescission, the health advocate can focus his or her efforts on stalling congressional action on the bill at the different stages of the legislative process to prevent the completion of action within the 45 day period. If the proposal is classified as a deferral, an advocate's task is more difficult. One of the houses of Congress must be persuaded to affirmatively adopt an impoundment resolution in order to ensure that the budget authority in question is made available.

If budget authority is required to be made available in accordance with the act and such budget authority is not released, the Comptroller General is empowered to bring a civil action in the United States District Court for the District of Columbia.[104] The purpose of the suit would be to require that the budget authority be made available.[105]

New Spending Authority[106]

Congress also addressed the problem of backdoor spending authority in the Budget Act. The act divides spending authority into three categories: contract authority,[107] borrowing authority,[108] and entitlement authority.[109]

Contract and Borrowing Authority

The Budget Act limits the circumstances under which legislation providing new contract or borrowing authority can be considered by Congress. Any member of Congress may lodge a point of order and prevent floor consideration of such a measure except where the legislation includes a provision that requires the enactment of an appropriations bill authorizing such spending authority.[110] This requirement is designed to afford the Appropriations Committees some control over spending authority.

This provision does not apply to new spending authority derived from a trust fund established by the Social Security Act, 90 percent self-financed trust funds or outlays of government corporations.[111] Legislation authorizing contract or borrowing authority is subject to the May 15 reporting deadline imposed by the act,[112] but it can be considered for enactment by Congress prior to the adoption of the First Concurrent Budget Resolution.[113]

Entitlement Authority

The act also subjects to a point of order floor consideration of any measure providing entitlement authority which would become effective before the beginning of the new fiscal year.[114] This provision was included to make entitlements subject to the reconciliation process.[115]

If the amount of new budget authority needed for the new fiscal year (including authority needed for the entitlement legislation) exceeds the appropriate allocation of new budget authority reported under the Concurrent Resolution, the legislation must first be referred to the Appropriations Committee of that house.[116] The Appropriations Committee may then amend the total new spending authority provided in any new entitlements to make them consistent with the reported allocation.[117] The committee may not, however, make substantive changes in the legislation.[118] The committee must report the measure with its recommendations within 15 calendar days after the bill was referred or it loses jurisdiction.[119]

Unlike other measures providing for spending authority, entitlement legislation is not subject to the May 15th deadline for filing committee reports.[120] The reason for this exemption is that neither house of Congress can even consider entitlement legislation until after the First Concurrent Budget Resolution is adopted, on or before May 15.[121] By delaying consideration of such legislation, Congress hoped to "enhance the significance of the first budget resolution and to strengthen congressional control over programs which are difficult to control once the entitlement has been enacted."[122]

Thus, health advocates seeking passage of new entitlement programs must not limit their efforts to the authorizing committees. Passage of authorizing legislation is a necessary precedent to establishment of any new program and most resources must necessarily be focused on the authorizing committees. However, if the Appropriations Committees refuse to appropriate sufficient funds, implementation of the new program may be delayed and passage ultimately jeopardized. Health advocates should therefore advise members of the Appropriations Committees and their staff of the need for and wisdom of maintaining the level of entitlement authority proposed in the legislation.

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[104] 31 U.S.C. §1406 (1976).

[105] *Id.* For a discussion of the scope of the President's authority to impound funds *see* Abascal and Kramer, *supra* note 34, at 177.

[106] New spending authority is spending authority which had not been provided by law at the time that section 401 of the Budget Act became effective. This includes any increase in or addition to spending authority that had already been provided by law prior to the section's effective date. 31 U.S.C. §1351(c) (1976).

[107] 31 U.S.C. §1351(c)(2)(a) (1976).

[108] 31 U.S.C. §1351(c)(2)(b) (1976).

[109] 31 U.S.C. §1351(c)(2)(c) (1976).

[110] 31 U.S.C. §1351(a) (1976).

[111] 31 U.S.C. §1351(d) (1976).

[112] 31 U.S.C. §1352(a) (1976). *See generally* note 75 *supra*.

[113] 31 U.S.C. §1324(a) (1976).

[114] 31 U.S.C. §1351(b)(1) (1976).

[115] *See* note 74 *supra*. *See also* S. CONF. REP. NO. 924, 93rd Cong., 2d Sess. 65, *reprinted in* [1974] U.S. CODE CONG. & AD. NEWS 3591, 3607.

[116] 31 U.S.C. §1351(b)(2) (1976).

[117] 31 U.S.C. §1351(b)(3) (1976).

[118] S. CONF. REP. NO. 924, 93rd Cong., 2d Sess. 65, *reprinted in* [1974] U.S. CODE CONG. & AD. NEWS 3591, 3607.

[119] 31 U.S.C. §1351(b)(2) (1976).

[120] 31 U.S.C. §1352(e)(1) (1976). Omnibus social security legislation which provides new budget authority and entitlement authority within the same measure also does not have to be reported by May 15. 31 U.S.C. §1352(e)(2) (1976); *Id.* at §1351(b).

[121] 31 U.S.C. §1324(a)(4) (1976).

[122] S. CONF. REP. NO. 924, 93rd Cong., 2d Sess. 60, *reprinted in* [1974] U.S. CODE CONG. & AD. NEWS 3591, 3602.

Revised Second or Third Concurrent Budget Resolution

After the Second Concurrent Budget Resolution has been adopted, any member of Congress can raise a point of order against consideration of any new legislation that would cause the budget authority or outlays for that year to exceed the levels agreed to in the Second Concurrent Resolution.[123] It is also out of order to consider any legislation that would reduce revenues below the levels set in the budget resolution.[124]

The hope was that any desired or needed changes in spending or revenue levels would be made within the framework of the congressional budget process. Such an approach underscores the "binding" nature of the budget resolution and maintains fiscal control over the budget.[125]

It sometimes becomes necessary to modify the figures set in the Second Budget Resolution due to congressional desire to enact a new program. The Budget Act provides for revision of the Second Resolution through passage of additional concurrent resolutions. Each such resolution reflects desired changes and revises the concurrent resolution most recently agreed to for the current fiscal year.[126]

This revised resolution can be adopted in conjunction with congressional consideration of supplemental appropriations or in response to updated figures for the current fiscal year contained in the President's budget.[127] In addition, Congress may wish to review its most recent budget resolution if sharp changes in the revenue or spending estimates are necessary due to major economic developments.[128]

V. A HYPOTHETICAL BUDGET-WALK-THROUGH[129]

During the Spring of 1979, health advocates decide to press for increased funding for the community health center program.[130] This program provides funding for the establishment of outpatient clinics in medically underserved urban and rural areas throughout the country. Advocates prepare position statements describing the importance of the program, the positive effects of the program on the poor, and the cost-effectiveness of community health centers in delivering needed health care.

During the Summer and Fall of 1979, health advocates meet with staff from the Health Services Administration (HSA) of the Department of Health, Education and Welfare to urge them to request increased funding for the program in the 1981 budget. Various figures and possible strategies are discussed.

The Administrator of the Health Services Administration approves the budget figure requested by the Bureau of Community Health Services for the community health center program. This figure ($400 million) represents a substantial increase in budget authority over the 1980 fiscal year ($320 million) and would allow a significant expansion of the program. This figure is later approved by the Assistant Secretary for Health, who administers the Public Health Service.

On October 1, 1979, the 1980 fiscal year begins. The Bureau of Community Health Services begins to obligate its appropriated funding for expansion of the community health center program into new areas and for upgrading of existing centers.

During October 1979, the budget of the Department of Health, Education and Welfare is assembled. In reviewing the proposed budget for the community health center program, the Assistant Secretary for Management and Budget for HEW questions the size of the requested increase. After reviewing the operation of the program, the budget increase is reduced to $350 million. The Health Services Administration, after reviewing the various changes in its budget, decides to appeal the decision on community health centers. The appeal is largely successful and a figure of $390 million is approved by the Secretary of HEW. The decision by the Secretary comes after a large number of telephone calls and letters by health advocates urging that the $400 million figure be approved.

The budget of the Department is then forwarded to the Office of Management and Budget (OMB) in late October. OMB, anxious to control costs, disapproves several aspects of the HEW budget including the proposed budget increase for community health centers. OMB recommends a 10 percent increase over the current budget for the program. The Department, after reviewing the various OMB changes, decides to include this issue in its appeals. Learning of the proposed reduction, health advocates contact the White House Domestic Affairs Council and attempt to persuade staff about the important role that community health centers play in improving service delivery. After negotiations, OMB approves a figure of $374 million for the program in late November.

During December and early January of 1980, the President's budget is completed and printed. The budget includes a figure of $374 million for community health centers.

On January 28, 1980, the President delivers his 1981 budget message to Congress. One of the items included in the President's message is an overall increase of $687 million for expanded health services to the poor and underserved. The $54 million increase in the community health center budget is included in this figure.

Shortly after the budget message, the actual budget documents are released. The budget describes the national health needs and the major federal health initiatives. It also describes gaps in the health care system. Based on this discussion, the President proposes the following budget for functional category 550, Health (in millions of dollars):

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123. 31 U.S.C. §1332 (1976).
124. *Id.*
125. S. Conf. Rep. No. 924, 93d Cong., 2d Sess. 64, *reprinted in* [1974] U.S. Code Cong. & Ad. News 3591, 3606.
126. 31 U.S.C. §1325 (1976).
127. S. Conf. Rep. No. 924, *supra* note 125, at 3603.
128. *Id.*
129. This budget walk-through is based on the 1981 Fiscal Year budget cycle. It is hypothetical in that some changes have been made from the actual figures and events.
130. The community health centers program is authorized by section 330 of the Public Health Service Act. 42 U.S.C. §254c (1976 & Supp. III 1979). This section authorizes $9,000,000 for fiscal year 1981 to be used for grants for the planning and development of centers. *Id.* at § 254c(g)(1). Another $463,000,000 is authorized for grants to existing centers and related entitites. The Secretary can also use these funds to assist centers in the planning and development of a prepaid health plan. *Id.* at § 254c(g)(2); 42 U.S.C. § 254c(d)(1)(C) (Supp. III 1979).

	1979 actual	1980 estimate	1981 estimate	1982 estimate	1983 estimate
Budget Authority	53,908	60,033	71,546	83,184	94,497
Outlays	49,614	56,563	62,449	70,801	79,914

The Budget also includes a breakdown of these figures by major programs. The figures for the community health center program are as follows:

Budget Authority (in millions of dollars)

Health Services	1979 (actual)	1980 (est.)	1981 (est.)
Community Health Centers	259	320	374

In addition, the text contains the following language:

> The 1981 budget proposes to expand health services funding for high-priority underserved areas through the community health centers program and the National Health Services Corps (NHSC). A proposed $54 million increase in 1981 budget authority above the 1980 level of $320 million would support 886 community health centers serving over 5 million people.

Starting in late January 1980, the Committee on the Budget of the Senate and the House Budget Committee hold hearings on the 1981 budget. Due to changed conditions, administrative witnesses present a revised budget request for health and other programs. These revised figures are $71.1 billion in budget authority and $61.9 billion in outlays.

The first witnesses at the budget hearings come from the Administration. They are followed during the next few months by witnesses from the private sector, Congressional Budget Office, and others. Health advocates request an opportunity to testify on the health portion of the budget, but are denied an opportunity. Written comments are sent to members of the House and Senate Budget Committees, however, setting forth views on such issues as the community health center program. In addition, meetings are held with key staff members to discuss the health budget figures.

In April, the House and Senate Budget Committees report differing versions of the First Concurrent Budget Resolution. The Senate Committee recommends budget authority of $70.7 billion and outlays of $61.7 billion for Fiscal year 1981. The House resolution provides budget authority of $71.5 billion and outlays of $61.8 billion. Health advocates initiate contacts with conference committee members to urge adoption of the higher House figures.

On May 23, 1980, the House and Senate Budget Committees agree on a conference report for the First Concurrent Resolution on the budget for Fiscal Year 1981. The committee report provides for budget authority of $71.1 million for health and outlays of $61.7 billion. The Conference Committee essentially splits the difference between the House and Senate figures. The Conference report is adopted in Congress on July 12, 1980.

The Conference Committee deliberations are conducted against a backdrop of budget balancing and deficit reduction fever. In order to implement these concerns, the First Concurrent Resolution directs the various authorizing committees to develop specific spending reduction proposals for the programs within their jurisdictions as well as revenue increasing proposals. These reconciliation instructions occupy the attention of the authorizing committees for much of the months to come.

Beginning in January 1980, the House and Senate Appropriations Committees also begin holding hearings on the appropriation for the Department of Health, Education and Welfare, including the community health center program. Witnesses from the Administration, Congress and the public testify. A coalition of public interest organizations is provided an opportunity to testify before the House Appropriations Committee. That testimony discusses the importance of preserving the direct service programs and specifically discusses the contribution of the community health center program to improving access to health care. The Appropriations Committees continue their deliberations through the Spring and early Summer of 1980.

On July 21, 1980, the President transmits his midsession review of the Fiscal Year 1981 budget. That midsession review confirms the fears of many that the economy has substantially worsened. May's balanced budget has now turned into a $30 billion deficit. Moreover, the failure of Congress to enact hospital cost containment has increased health outlays for the Medicare and Medicaid programs.

Also on July 21, 1980, the House Budget Committee reports the Omnibus Reconciliation Act of 1980. That bill includes a variety of spending reduction and revenue measures to conform to the First Concurrent Resolution. Health advocates have lobbied with substantial success in limiting spending reductions to those programs that will have a minimum adverse effect on the poor. The Reconciliation Act is referred to the Senate for further action.

By the time that Congress returns from the August recess, the budget situation has continued to worsen and fragile legislative coalitions have begun to falter. Because of continued controversy over federal funding for abortions as well as other issues, any chance of enactment of an appropriations bill for the Department of Health and Human Services has disappeared. The House passes an appropriations bill on August 27, 1980, but Senate agreement is unlikely. Congress therefore begins work on a continuing resolution for appropriations for several agencies.

A continuing resolution is finally adopted by Congress on October 1, 1980, the first day of the new fiscal year. Because of increases in mandatory entitlement programs (especially Medicare and Medicaid), many discretionary programs receive reduced or static appropriations. Generally, appropriations are set at either the 1980 level or the House appropriations bill level, whichever is lower. The resolution extends appropriations through December 15, 1980.

No specific sum is earmarked for the community health center program within the general appropriation for the Public Health Service. Based on the total appropriation, the Department of Health and Human Services authorizes the community health center program to operate at the equivalent annual level of $325 million, a $5 million increase over 1980.

By October 1, 1980, the beginning of the 1981 Fiscal Year, no Second Concurrent Budget Resolution has been passed despite the September 15 deadline. No 1981 appropriations bill for the Department of Health and Human Services has been passed despite the September 8 deadline. No reconciliation bill has been passed despite the September 25 deadline. Much work is left to be done in the lame duck session after the election.

On November 20, 1980, the Congress finally adopts a Second Concurrent Budget Resolution for Fiscal Year 1981. Because of the worsening economic situation and a new desire to increase defense spending, funds for social programs, including the budget category for health, are substantially reduced. A coalition of consumer groups, labor, and public interest organizations lobbies with limited success to minimize these reductions. Budget authority for health is reduced to $68.55 million; outlays are set at $63.15 million.

At this same time a massive conference committee is completing deliberations over the Omnibus Reconciliation Act of 1980. That committee finally reaches agreement on November 26, 1980, and the act is passed by Congress on December 3, 1980, and approved by the President. The Senate version of the health reduction would have been extremely detrimental to the poor. Health advocates are able to persuade conferees to eliminate many of the worst provisions in the conference version. The community health center program is not affected.

As the congressional session nears its close, so does the continuing resolution for appropriations. Just before the end of the session, on December 15, 1980, the Senate finally agrees to the House version of the continuing resolution to extend funding for federal agencies, including the Department of Health and Human Services, through no later than June 5, 1981. No changes are made in the funds available to the community health center program.

At least one more attempt at an appropriations bill therefore will have to be made for the remaining four months of the 1981 Fiscal Year. In addition, the continued worsening of the economy might necessitate a revised Second Concurrent Budget Resolution for 1981, as spending and the budget deficit exceed estimates. The Budget Act has survived intact; the budget process has not yet realized expectations.

CONCLUSION

The Congressional Budget and Impoundment Control Act is now nearly seven years old. Congressional implementation of its requirements has been, at best, uneven. Missed deadlines, continuing resolutions instead of appropriations bills, and inadequate budget forecasting have often characterized the federal budget experience. Most recently, the reconciliation process has provided a potentially dangerous opportunity to circumvent the normal process for consideration of legislation and adopt amendments to existing programs without hearings or an opportunity for public input.

The budget process has become a crucial stage in the legislative process and can no longer be ignored by health advocates concerned with protecting the interests of low-income clients. The potential for benefit and harm is simply too great.